

THE NIH RECORD

Still The Second Best Thing About Payday

Historian's Perspective

When the 'Gold Standard' Was Controversial

By Rosser Matthews

For many researchers at NIH, the usefulness of large population-based studies seems self-evident. In its most rigorous form as a randomized controlled clinical trial, it is often held up as the "gold standard" for scientific inquiry. However, it is important to remember that today's "taken-for-granted" assumptions often conceal yesterday's controversies. One interesting example of this phenomenon involves the National Collaborative Perinatal Project, which was launched by the National Institute of Neurological Diseases and Blindness in the 1950s.

Conceived by the institute's first director Dr. Pearce Bailey, the project followed more

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Nutrition Month Observed at NIH

March is National Nutrition Month, and the theme for 2002, developed by the American Dietetic Association, is "Start Today for a Healthy Tomorrow." The theme reminds us that daily food intake is an important component of overall health and that it is never too late to improve health by improving diet.

The 2000 Dietary Guidelines for Americans provide valuable ABC's: Aim for fitness, aim for a healthy weight, and be physically active each day (about 30 minutes of moderate activity/day for adults). Build a Healthy Base—let the food guide pyramid influence your food choices. Choose a variety of grains daily, especially whole grains. Choose a variety of fruits and vegetables daily. Keep food safe to eat.

Also, choose sensibly—ADA recommends a

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U.S. Department
of Health and
Human Services
National Institutes
of Health

February 19, 2002
Vol. LIV, No. 4

Interesting Challenges Ahead

Ethicists Grapple with Era of Genetic Enhancement

By Rich McManus

As medicine gets more clever at manipulating genes to treat human ailments, society also verges closer to hard decisions about which interventions are aimed at correcting problems, and which interventions have the ethically more troubling aspect of enhancing some facet of the human organism.

Such capability sounds like science fiction, but the questions are already arising in philosophy and bioethics departments the world over; on Jan. 31, former NIH ethicist Dr. Eric Juengst offered an overview of current academic thinking in a talk at Lipsett Amphitheater on the topic, "Anticipating Genetic Enhancement: Professional, Ethical and Public Policy Issues." It was the first lecture in an NHGRI-sponsored series titled, "The Human in Genome."

Until the advent of recombinant DNA research in the early 1970s, no one had to worry much about the possibility of medi-

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Ethicist Dr. Eric T. Juengst

Stigma, Global Health Research Explored

By Jennifer Cabe and Barbara Sorkin

The Fogarty International Center recently convened an international conference on "Stigma and Global Health: Developing a Research Agenda" in partnership with 14 institutes and offices and seven governmental and non-governmental organizations. The conference examined the social and cultural determinants of stigma, how it prevents people from seeking or getting treatment for disease, and potential future research opportunities to address health challenges in the United States and the developing world.

More than 250 participants from 30 nations, including 23 developing countries, discussed stigma associated with HIV/AIDS, mental health, epilepsy, physical anomalies, alcohol and drug abuse, physical and sexual abuse, genetics, race and gender.

The 3-day conference was cochaired by FIC director Dr. Gerald

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than 50,000 women from the time of their pregnancies until their children reached age 8. The study, which collected data into the 1970s, generated an enormous amount of empirical information. In a 1986 editorial in the *New England Journal of Medicine*, epidemiologist Nigel Paneth praised the support that had been provided by NIH and singled out Dr. Richard L. Masland, director of NINDB from 1959 to 1968: "The kind of vision that Richard Masland demonstrated when he created the National Collaborative Perinatal Project may yet be found among our funding agencies. Research is costly, but childhood neurologic handicap is costlier still."

Anyone who read only Paneth's comments might assume that the scientific merit of the NCPP had never been questioned. The historical record, however, indicates otherwise. In the 1950s, the human embryology and development study section voiced concern that large amounts of money would be spent without adequate oversight. In 1965, a presidential committee urged that all collaborative projects be kept "as small as possible." In 1967, Charles W. Whalen, a Republican Congressman, cited the \$75 million that had been spent on the NCPP as an example that "the taxpayers' dollars are not always wisely spent."

Despite these criticisms, the NCPP survived. By promoting interdisciplinary research, the project helped establish the contemporary field of pediatric neurology. Also, it was one of a number of studies that led researchers to question the belief that birth asphyxia (suffocation) often contributed to cerebral palsy.

What is the historical lesson of the NCPP? It can serve as an antidote to complacency. In an era when "evidence-based medicine" is widely touted (often in the name of cost-effectiveness), it is important to remember that the process of collecting empirical evidence can itself be a very costly (and potentially controversial) process. ■

Randy Schools (c), president of the NIH Recreation and Welfare Association, receives a plaque in recognition of the outstanding and continuous support that he and the R&W staff have provided to the fire safety programs at NIH. Making the presentation are Bill Magers (l) and Richard Shaff of the Emergency Management Branch, Division of Public Safety, Office of Research Services.



'JobNet' Eases Career Contacts

In order to make job searching easier for young scientists holding fellowships at NIH, two fellows have created JobNet. The original idea was to establish an alumni database so former NIH fellows who have established careers could provide advice exclusively to current fellows. Drs. Christine Brennan and Yvonne Szymko created the initial JobNet database, which has been expanded to include career contacts from all backgrounds; however, it still can only be viewed from within NIH.

Currently there are volunteers willing to give advice on careers in such fields as science writing, regulatory affairs, teaching, signal transduction, immunology and bioinformatics. Volunteer contacts often have positions available at their facilities and are eager to hear from NIH fellows.

The JobNet site is at <http://felcom.nih.gov/Careers/Jobnet/index.html>. NIH fellows and employees can view the current career contact listings, and scientists in permanent positions can complete a form to volunteer as a career contact. Members of the NIH fellows' committee maintain the site by advertising, recruiting volunteers and periodically updating the site. Fellows wishing to help maintain or add to the resource should contact Dr. Diane Lawrence (lawrencd@ninds.nih.gov) or Dr. Joanna Kirman (jkirman@mail.nih.gov) for more information. ■

Pulmonary Sarcoidosis?

Call NIH at 1-800-411-1222 (TTY: 1-866-411-1010) for a study comparing a medication called pentoxifylline and a placebo (sugar pill). Must be on standard steroid treatment. ■

NIH RECORD

Published biweekly at Bethesda, Md., by the Editorial Operations Branch, Division of Public Information, for the information of employees of the National Institutes of Health, Department of Health and Human Services. The content is reprintable without permission. Pictures may be available on request. Use of funds for printing this periodical has been approved by the director of the Office of Management and Budget through Sept. 30, 2002.

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The NIH Record reserves the right to make corrections, changes, or deletions in submitted copy in conformity with the policies of the paper and HHS.

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ICs Awarded for Powwow Outreach

The pilot NIH Native American Powwow Outreach Initiative was developed last spring to recruit Native Americans to NIH and to support the elimination of health disparities by disseminating health information. Dr. Yvonne Maddox, acting deputy director of NIH, has been the principal supporter of the effort since it was first proposed by the OD Equal Employment Opportunity Office. After seven powwows this year, Maddox and the OD EEO office thanked 27 staff members from seven ICs at an awards program.

Maddox congratulated the OD EEO office and the IC partners for making the initiative a success. The awardees gave up weekends to travel to remote rural locations in Maryland and Virginia. Among the awardees were EEO officers and staff from NIDCR, NLM, CIT and NIMH, as well as staff from NIA, NIAID and OD.

Hilda Dixon, OD EEO manager, described the initiative and its accomplishments using pictures of the various powwows. On the recruitment half of the initiative, the powwows produced nine resumés submitted by Native Americans. Two people were hired, one by NIDCD and the other by NHLBI. The other seven resumés are being reviewed by IC managers for possible employment.

The other half of the initiative—helping to eliminate health disparities—proved to be gratifying to the awardees. It appeared early in the pilot initiative that many Native Americans had never heard of the National Institutes of Health. NIH'ers were both welcomed and appreciated at each powwow location.

Many attendees were surprised to know that information from NIH is free. There were also requests for specific health issues that required research and followup after the powwows.

During her presentation at the awards ceremony, Dixon recalled that one Native American family asked a more specific question: Did NIH have any information on their rare disease? In following up on the request, the OD EEO office obtained information from the NIH Office of Rare Diseases and forwarded it to the family. "It is amazing that, at a powwow, we located a Native American family with a disease so rare that it has only been diagnosed in 15 other families throughout the world," Dixon noted. The family is now participating in a clinical

trial and hopes to benefit themselves and others.

Many lives were helped by the information shared on a wide range of health issues, according to remarks made by participants at the powwows:

"The Native American's life is really changed by NIH," said one attendee, "but actually giving out information at the powwow, that's just great. As a former commissioned officer with the Indian Health Service and health practitioner, I can only say, 'Thank you, NIH!'"

An instructor on a field trip for teaching on diversity said, "This is the best and most informative booth in the whole powwow!"

The awards program was held last November, which is National American Indian and Alaska Native Heritage Month. The awards consisted of a crystal box and a framed certificate of appreciation. The National Library of Medicine received a special award for its constant support of and ongoing participation in the initiative. In addition, the awardees' supervisors were praised for supporting their staff.

The program closed with a reception, its reunion atmosphere demonstrating the cohesive relationship established from working together on powwows. ■



Dr. Yvonne Maddox

STEP Module on 'Big Science'

The staff training in extramural programs (STEP) will present an Administrative Strategies Module titled "Big Science, Big Challenges," on Friday, Mar. 1 from 8:30 a.m. to 4:30 p.m. in Masur Auditorium, Bldg. 10.

The explosion of scientific advances in many areas of research has created more opportunities than ever for funding "big science"—large, often expensive, multi-disciplinary, multi-institutional projects that frequently involve international collaborations and resource networks. The expected eventual decrease in the growth of the NIH budget is likely to exacerbate many of the difficulties in funding and managing "big science" projects. The module will use case studies to discuss examples of creative strategies for identifying and overcoming barriers to establishing and managing big projects. Issues to be addressed include: Under what circumstances should NIH support Big Science? What innovative approaches have been used to promote and support large, multi-disciplinary research collaborations? How do you determine the most appropriate organizational and funding models for these projects? What are the barriers in reviewing, funding and managing Big Science projects? What creative approaches have been used to overcome these barriers? How do you decide when and how to phase out these projects? Attendance earns ESA credit. ■

Alumni Weigh In on Fence

The NIH Alumni Association's board of directors recently passed a resolution opposing erection of a fence around campus. But it allowed that, if security needs call for such a barrier, it should be "not only attractive and unobtrusive, but (also) behind the buffer zone called for in the NIH Master Plan rather than on the edges of the campus." The NIHAA claims a fence would reduce the "academic ambiance" of the campus, turning it into "Fortress NIH." A fence could also offend NIH neighbors and harm recruitment of fellows and staff, according to the board's resolution, which passed unanimously.

Kington Named NIAAA Acting Director

Dr. Raynard S. Kington has been named new acting director of the National Institute on Alcohol Abuse and Alcoholism.

"I am honored to have this opportunity to join the dedicated scientists and staff at NIAAA in their vital mission against alcohol abuse and its myriad biomedical and psychosocial consequences," said Kington.

If Kington's name sounds familiar, it should—in November 2000 he became NIH associate director for behavioral and social sciences research and director of the NIH Office of Behavioral and Social Sciences Research, positions he will retain while serving as NIAAA acting director.

"I've come aboard at a very exciting time at NIAAA. In early January, I had the pleasure of taking part in the second National Conference on Leadership to Keep Children Alcohol Free, an initiative of NIAAA and the Robert Wood Johnson Foundation. With the help of 33 spouses of governors from across the country, the leadership initiative is alerting our nation to the critical public health problem of underage drinking and mobilizing action throughout our society to prevent it."

In early March, Kington will kick off a fetal alcohol syndrome public awareness campaign in Washington, D.C. Cosponsored by NIAAA, the campaign will include radio public service announcements and a variety of printed materials that inform women of the dangers of drinking alcohol during pregnancy.

"In April," noted Kington, "NIAAA will release a report on college drinking prepared by a group of distinguished educators and alcohol researchers. Many will be alarmed, I believe, by the extent of the harmful consequences of excessive drinking by college and university students revealed in this report."

Also in April, the fourth National Alcohol Screening Day, held this year on Apr. 11, will provide free confidential screening and information to individuals concerned about their own drinking or that of a friend or family member. Screening will be conducted at colleges, health centers, hospitals and clinics across the country.

Kington earned undergraduate and medical degrees from the University of Michigan and then completed his residency training in internal medicine at Michael Reese Medical Center in Chicago. He attended the University of Pennsylvania as a Robert Wood Johnson clinical scholar, earning his M.B.A. and his Ph.D. in health policy and economics from the Wharton School. Board-certified in internal medicine, geriatric medicine, and public health and preventive medicine, Kington has primarily been interested in studying social factors as determinants of health. ■



Dr. Raynard S. Kington has been named new acting director of the National Institute on Alcohol Abuse and Alcoholism.

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diet that is low in saturated fat and cholesterol and moderate in total fat. Choose beverages and foods to moderate your intake of sugars. Choose and prepare foods with less salt. And if you drink alcoholic beverages, do so in moderation.

For information about Nutrition Month activities at NIH, visit the Division of Nutrition Research Coordination web site at www.dnrc.nih.gov. The site also provides nutrition messages prepared especially for NIH employees on the topics of the 5-A-Day Program, diet and cardiovascular disease, overweight and obesity, physical activity, eating out and dietary supplements.

A special presentation on "The DASH Studies" will be given by Dr. Frank M. Sacks on Thursday, Mar. 7 in Rockledge II, Conf. Rm. 9112 from 1:30 to 2:30 p.m. Sacks is professor of cardiovascular disease prevention in the department of nutrition, Harvard School of Public Health. All NIH employees are welcome.

DASH stands for Dietary Approaches to Stop Hypertension, and the studies were supported by NHLBI. The DASH diet is rich in fruits, vegetables, and low fat dairy foods and reduced in total and saturated fat. Results from the DASH-sodium trials (where subjects received the DASH diet and a reduced sodium intake) showed lowered blood pressure for all population subgroups studied. Call 594-8822 for more information about the presentation.

The dietetic interns at the Clinical Center will post a display with contests and cooking demonstrations from noon to 1 p.m. in the Bldg. 10 main cafeteria on Thursday, Mar. 21 and in the Bldg. 31 cafeteria on Friday, Mar. 22. They will offer recipes, handouts and prizes.

Also, be on the lookout for your colorful NIH desk-to-desk National Nutrition Month flyer. It will be in your mailbox in early March and will provide information about how to improve your diet and increase your physical activity. ■

NIH/MC Summer Classes

The NIH/Montgomery College Partnership has announced this year's summer classes. Courses will be offered in the evening after working hours at Executive Plaza South. HRDD is currently accepting nominations for the summer session, which will include the following classes:

Medical Terminology I; Math Refresher; General Psychology; Introduction to Business; English Pronunciation for Non-Native Speakers; English Refresher.

For more information about the classes, visit <http://LearningSource.od.nih.gov> or call 496-6211. ■

Seminar Offers Help on Avoiding Caregiver Burnout

By Sophia Glezos Voit

When a person develops a mental illness, family members and others have the power to influence the recovery process favorably or otherwise, said clinical psychologist and NIMH researcher Robert Heinssen at a recent seminar for NIH staff. "Studies show that the power for good is rooted in taking care of yourself."

While getting enough exercise, sleep and nourishing food is a good idea if you want to maintain health, there's more to self-care when a loved one is sick.

"Most people feel selfish meeting their own needs,"

Heinssen said, speaking on coping with mental illness in the family at a recent session of the Seminar Café, held monthly at the Neuroscience Center on Executive Blvd.

"So, they keep doing and doing, neglecting their own needs, until eventually they burn out. No one benefits, especially not the patient. But 'selfishness' and 'healthy self-interest' are not the same."

Although Heinssen's experience is in treating people with severe mental illness, he said studies show that the importance of meeting one's own needs also applies to loved ones of people suffering from other types of medical conditions.

Dealing with illness and its different stages—whether temporary or long-term, whether the brain is affected or another organ—brings on challenges and pulls on many different emotions, both for the individual and the family members; it's important to know how best to regulate these feelings.

"Significant others can either bolster a person's ability to tolerate the stress of an illness or can contribute to the worsening of symptoms," Heinssen said. "When we don't take care of our own needs, we're more likely to become irritable, short-tempered, judgmental, resentful—which can have a negative impact on the person who's struggling to get better."

Studies show that supportive, flexible and enduring relationships can "facilitate a person's stability and recovery," he said, whereas interactions characterized by "criticism, over-control or rigid expectations can accelerate the process of active symptoms."

Although each illness has its own course, said Heinssen, in many cases long-term outcome can be favorably altered. Even though family support is only one factor in medical outcome, taking self-care seriously can help family members "begin to modify the trajectory of a loved one's condition." In no way, he cautioned, does this mean that family members cause illness or that they're to blame if their loved one doesn't get well. "But since relationships are interactive, it makes sense to play as positive a role as you can."

Heinssen said self-care is a three-pronged tool in the service of healing: self-education about the illness in question; establishment of one's own social support system; and taking the steps to preserve one's mental health.

Self-education means learning about the disorder's symptoms, the course of the illness, treatment

"When we don't take care of our own needs, we're more likely to become irritable, short-tempered, judgmental, resentful—which can have a negative impact on the person who's struggling to get better."

options, and effective approaches to navigating the health care system.

"Because the mental health care system, in particular, is fraught with complexities such as confidentiality issues and limits on health-insurance coverage, it is especially important to learn how to use it to your advantage," Heinssen said.

The next step, establishing your own support system, can include having close friends and family ties but it also involves attending support groups with other people who are dealing with similar family issues.

Just as important as support groups, he added, is the need for family members to develop and maintain interests that are separate from their relationship with the individual who is recovering.

"It means taking positive steps to ensure your own mental health," Heinssen said. "Getting out and having a good time, laughing and having fun, setting limits for yourself, meeting your recreational needs, all of it helps to preserve your relationship for the long haul."

As for preserving one's mental health, there are many legs to this third self-care step. One of them may include having your own therapist, someone in whom you can confide about your own struggles and from whom you can learn new coping strategies.

The Seminar Café's Feb. 26 seminar, presented by Dr. Matthew Rudorfer, chief of the NIMH Somatic Treatments Program, will address what science has discovered about the mental health effects of exercise. During Brain Awareness Week, on Mar. 12, Drs. Barbara Radziszewska and Bernard Ravina of NINDS will focus on research findings about how to prevent stroke or minimize damage if it occurs.

All seminars, presented in layman's language, are held from 2-3 p.m. in the café area of the Neuroscience Center cafeteria, located at 6001 Executive Blvd., in Rockville. To register or to request any reasonable accommodation, call 443-4533 or write to sglezos@nih.gov. ■

Healthy Families Needed

NIAAA is seeking parents and their healthy adolescent children, ages 12-17, to participate in a study involving an interview and a brain scan. No medication is involved. Compensation is provided. Call 594-9950 for information.

Sailing Club Open House, Feb. 28

The NIH Sailing Association will hold an open house on Thursday, Feb. 28 from 5 to 8 p.m. at FAES House on the corner of Old Georgetown Rd. and Cedar Ln. Have you longed to cruise on the Chesapeake Bay? Would you like to learn to sail? Does the idea of racing sailboats appeal to you? Can you imagine being part of a group of fun, skilled sailing instructors, enthusiasts and boat owners? Check it out at the NIHSA open house. Admission is \$5 at the door and includes pizza and sodas; \$2 for beer or wine. Drop by if you are interested in instruction and sailboats for charter, racing, cruises or parties.

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cally reengineering human beings to emphasize this or that desirable trait, said Juengst, who was the first chief of the Ethical, Legal and Social Implications Branch of what was initially the National Center for Human Genome Research; he left in 1994 and is now at the Center for Biomedical Ethics at Case Western Reserve University.

"Peoples' imaginations leaped at what we might do with genes and splicing," once news of the technique spread, he said. "The question arose, 'Might we improve on the species' design?'"

A science fiction book published in 1978 forecast men modified to live underwater, humanoids who could inhabit space sans spacesuits, and a class of warriors bred only for battle. But before any such figments became thinkable, there was an easy consensus about the limits of modifying our own kind, said Juengst: "Whatever we do, we shouldn't redesign the species." This stricture relied on two fundamental principles—no one is wise enough to imagine what is ideal in the first place, and the lessons of eugenics movements of the past provide ghastly evidence of the danger of such an effort.

While people felt, almost instinctively, that science should not cross the line between improvement (to thwart a disease or disability) and enhancement (to confer some kind of advantage), there was—prior to the establishment of the recombinant DNA advisory committee at NIH (the RAC)—no rule-making body to consider an ethical path society might take in the shadow of the new science. The RAC helped make two ideas explicit: we ought not to infect the germline with recombinant DNA molecules, and we shouldn't go beyond therapy into the realm of enhancement.

But as medical therapies became more sophisticated, blurring the line between addressing a given ailment and imparting novel, and beneficial, qualities to humans (for example, revving up the immune system to fight cancer), ethicists had new and deeper questions to ask. "We had to remind ourselves, 'What was it about enhancement that we didn't like?'" said Juengst.

An unusually plainspoken philosopher, Juengst used common parlance to categorize these objections:

◆ "It's not nice to fool mother nature"—There is a normative sense that persuades us that the way we are now is the right way for some reason; that's how God or evolution made us. Also, we don't know the consequences of

upgrading any particular trait; there might be an associated loss. Who knows what we might be destroying by trying to enhance a given trait?

◆ "You can never be too rich or too thin"—Since access to genetic enhancement would be available primarily to those who could afford it, it might exacerbate social disparities. "If the rich could improve themselves biologically, then the rich would truly get richer," noted Juengst.

◆ "...where all the children are above average"—Borrowed from Lake Wobegone of radio and literature, this slogan warns of the corruption of parental expectations if better IQs and higher cheekbones were to become a matter of trips to the doctor. As Juengst wondered, "Is the unconditional love we are supposed to have for our children born of necessity? And what if it weren't?"

◆ "Is beauty in the eye of the beholder?"—How tolerant would we be of diversity if people had the means to transform themselves into a culture of Schwarzeneggers and Jennifer Lopezes? What would become of the aged, the disabled, the non-hot?

Having led the audience into these deep waters, Juengst offered options society might choose, including careful assessment of the risk associated with therapies that might potentially confer enhancement, and evaluation of access to such enhancement, should it become possible. To get started, it helps to consider what is normal function and what is disease.

On the "normal" side of the ledger, "We know what's normal in a statistical sense, and there are



Juengst lectures at his alma mater.

PHOTOS: ERNIE BRANSON

Human Genome Lecture Series

Dr. Eric Juengst's talk was the first in a series of lectures on the ethical, legal and social implications of genomic research, sponsored by the National Human Genome Research Institute. All are given from 11:30 a.m. to 1 p.m. in Lipsett Amphitheater, Bldg. 10. The remaining schedule is as follows:

Apr. 18, "Translating Genetic Advances into Improved Health Outcomes," Dr. Wylie Burke, department of medical history and ethics, University of Washington.

May 23, "Pharmacogenomics and Population Groups," Mark Rothstein, Herbert F. Boehl chair of law and medicine, University of Louisville.

June 20, "White and African-American Genetic Explanations for Gender, Class and Race Differences," Dr. Toby Jayaratne, Institute for Research on Women and Gender, University of Michigan.

For more information and special accommodation call 402-4997 or visit www.nhgri.nih.gov/CONF/Lectures/2002NHGRI.html.

treatments that can return you to the normal range if you've fallen out of it—that's medicine," Juengst explained. "Enhancements are interventions that would lift you out of the normal range. But are we going to recognize enhancement when we see it? The problem is where to draw the line in the normal range. Do you do it at (renowned physicist) Stephen Hawking-level intelligence?" What about cancer patients who get an improved ability to seek out and destroy cancer cells? Or new therapies for reducing high cholesterol that saturate the body with LDL receptors, turning people into super cholesterol-soppers? These therapies confer abilities that are "abnormal," but they are also helpful.

Juengst posited a "preventive model" whereby as long as a therapy helps people avoid disease, it therefore fits into the standard healthcare paradigm. "But the development of a superhuman ability to resist disease is likely to shift the 'enhancement line.' Still, it seems legitimate because it helps avoid suffering." By the year 2020, we are likely to find ourselves asking, "If we can treat the individual, why not their successors (via germline therapy)?"

If you look not at what constitutes normality, but at disease states, you can also find ethical direction, Juengst continued. Consider the case of progeria, or drastically sped-up aging. "If we could slow aging in a patient with this disease, that would be great. But what are the limits of aging? When is it appropriate to oppose the process?"

Lest people think that such questions only preoccupy dreamers, he pointed out that the American Academy of Anti-Aging Medicine has some 10,000 members devoted to extending the range of a healthy lifespan, and that the company Geron is avowedly interested in slowing cellular aging. Will there be a temptation to apply what, for progeria, might be therapy, to an "off-label" use to simply extend a life already replete with advantage?

That led to a discussion of how to regulate use and development of new technologies that was as rich in example and potential danger as the foregoing discussion. Terms such as "genetic Maoism" (deliberately hampering the genetically endowed so as to achieve classlessness) and "trickle-down genetics" (wherein enhancements would be bundled with the obligation to work for the benefit of the unenhanced) hint at the difficulties Juengst foresees for the coming half-century.

Teasing out where the "enhancement" line lies in genetic medicine "is going to be more complicated than we thought it was going to be," he concluded. He anticipates an eventual congeries of policy approaches, some NIH-based, others at the level of professional caregivers. "But I suspect that the issues of tolerance and diversity will only be more important as time goes on." ■

NIH-FDA Analgesic Development Workshop

Finding ways to enhance the development of new drugs for treating pain is the focus of a workshop to be convened by NIH and the Food and Drug Administration on Mar. 13-14 in the Natcher Conference Center.

While pain is a universal experience that is usually episodic and short-lived and requires only temporary treatment with over-the-counter and non-prescription analgesics, pain associated with some diseases can become chronic. Often such pain is inadequately treated because of the limitations of currently available prescription drugs. The impact on quality of life can be substantial. Surveys show that approximately 34 million adults suffer from some form of chronic pain and that 75 percent of patients with advanced cancer experience moderate to very severe pain. An estimated 30-80 percent of HIV-infected patients experience pain that is not adequately relieved by current drugs, while severe, unrelieved pain is reported by 40 percent of the population at end-of-life.

The main limitation on the development of new drugs for pain relief may not be scientific, but practical. The process of safety and efficacy testing in clinical trials is becoming the bottleneck in clinical innovation and improved pain treatment.

The workshop will identify ways to address clinical needs in pain management by enhancing the analgesic drug development process from the identification of novel molecular targets to the introduction of new pain medicines. To register, visit www.betah.com/betah/conferences/nih-fda. ■

NIH Observes African American History Month, Feb. 25

NIH's annual African American History Program will be held on Monday, Feb. 25 at 1:30 p.m. in Lipsett Amphitheater, Bldg. 10. The theme of the observance is "Celebrating Pioneers—Standing on the Shoulders of the Past."

Historian and civil rights activist Roger Wilkins will deliver the keynote address. He is a professor in the Clarence J. Robinson history and American culture department at George Mason University. During the Johnson administration, Wilkins served as assistant attorney general. Also a distinguished journalist, he has written for the *New York Times* and the *Washington Post*, where as a member of the editorial page staff he shared a Pulitzer Prize in 1972 for Watergate coverage. Wilkins's acclaimed autobiography, *A Man's Life* (1982), was reprinted in 1991. His latest book is *Jefferson's Pillow: The Founding Fathers and the Dilemma of Black Patriotism*.

Also scheduled to participate is classical actor and griot Bill Grimmette, who will portray Benjamin Banneker, astronomer and surveyor of the nation's capital. ■



Roger Wilkins

STIGMA, CONTINUED FROM PAGE 1

Keusch and Dr. Arthur Kleinman, professor of medical anthropology and psychiatry at Harvard University.

What Is Stigma?

Stigma has been defined as a deeply discrediting attribute that reduces a person to one who is in some way tainted and can therefore be denigrated. It is a pervasive problem that affects health globally, threatening an individual's psychological and physical well-being. It prevents individuals from coming forward for diagnosis and impairs their ability to access care or participate in research studies designed to find solutions.

Much attention has been paid to the plight of the stigmatized, including those with AIDS or suspected to have AIDS, those with leprosy, and those suffering from mental disorders. But stigma goes beyond these conditions to include some that are no longer stigmatized in the developed world but continue to draw disapproval in resource-poor countries.

"Stigmatization of certain diseases and conditions is universal across all countries, all societies, all populations," said Keusch. "At this conference, for the first time, we looked at a whole set of conditions that result in stigma—physical, behavioral, psychological—and gained a better understanding of the mechanisms behind stigma. We identified gaps in the current understanding of stigma's impact on health, and highlighted the research opportunities at the individual, household, community and social system level."

Expert Speakers and Participants

The conference brought together participants from many areas of expertise, including public health, social and political science, genetics, epidemiology, media and communication and law.

In the keynote address, Dr. Kay Redfield Jamison, professor of psychiatry at Johns Hopkins University School of Medicine, provided personal and professional perspectives on stigma, noting that it discourages patients from seeking optimal treatment and living full, productive lives. Jamison, a leading expert on serious mood disorders and the recipient of a 2001 MacArthur Foundation "genius" award, spoke of her personal experience with manic-

depressive illness, recounted in her award-winning memoir, *An Unquiet Mind*.

Conferees updated the working definition of stigma, developing methods for measuring its occurrence and impact, developing interventions, and considering the need for research to evaluate interventions. The groundlaying discussions were followed by personal accounts of the impact of stigma.

A recurrent theme was the cycle in which individuals with stigmatizing conditions are negatively stereotyped and socially isolated, resulting in discrimination and disenfranchisement. Dr. Pablo Farias of the Ford Foundation noted that, as a result of stigmatization, societies sometimes allocate fewer resources to research and treatment of stigmatized conditions. He reported that Mexico, with a population of 100 million, has only 5,500 psychiatric beds. This shortage results in long waits for hospitalization, even for the severely ill.

The role of education in alleviating stigma and the influence of the media on public opinion were also considered. Bill Lichtenstein, an award-winning filmmaker and journalist who has himself experienced manic-depressive illness, spoke about the prevalence of negative stereotypes of the mentally ill in television and film and about his efforts to use these media to increase public understanding of mental illness. Dr. Martin Fishbein of the Annenberg School for Communication at the University of Pennsylvania highlighted the pressing need for rigorous research on the impact of the media on public image and behavior.

On the final day, participants focused on associations between race, gender or sexual orientation, and stigmatizing conditions, and on research and other actions that may decrease stigma and its effects. Scott Burris, professor of law and public policy at Temple University and Johns Hopkins University, said that while the law can be used as a tool to deter and provide a remedy for some harmful effects of discrimination resulting from stigma, effective enforcement ultimately depends on the social status of the affected group. Dr. Florence Baingana, mental health specialist at the World Bank, spoke about the tendency of stigma to perpetuate health inequalities, and the need for researchers to better understand the policy-making



Dr. Sumiti Solomon of the YRG Centre for AIDS Research and Education in India speaks at the conference on stigma.

At the Stigma and Global Health conference, shown (from l) are moderator and conference cochair Dr. Gerald Keusch, FIC; Dr. Florence Baingana, the World Bank; Scott Burris, Temple University and Johns Hopkins University; Dr. Carl Bell, University of Illinois and Community Mental Health Council and Foundation; Dr. Partha Majumder, Indian Statistical Institute, Calcutta; and Dr. Richard Parker, State University of Rio de Janeiro and Columbia University.



process, so they can work to ensure that research results have an impact.

Recommendations emerging from the meeting included the need for interventions to be carefully targeted to the conditions, groups and individuals concerned. Several groups emphasized that the interaction of researchers with an individual or family may in itself confer stigma; it is important to take measures to avoid this stigma, both for the sake of the affected groups and in the interest of enabling further research.

Kleinman commended participants for the richness of the evidence brought forward and the range of perspectives on a complex phenomenon. "This meeting has reinforced our conviction that there is a need for international stigma research, and that there is indeed a researchable agenda."

A video archive of the conference, as well as background papers, are available at www.stigmaconference.nih.gov. ■

Duke, Pitt Training Programs Offered

The deadline for applying to the 2002-2003 NIH-Duke Training Program in Clinical Research is Mar. 15. Designed primarily for clinical fellows training for careers in clinical research, the program offers formal courses in research design, statistical and decision analysis, research ethics and research management.

Courses for the program are offered at the Clinical Center by means of videoconferencing from Duke University or on-site by adjunct faculty. Academic credit earned by participating in this program may be applied toward satisfying the degree requirement for a master of health sciences in clinical research from Duke School of Medicine.

For more information about course work and tuition costs, visit <http://tpr.mc.duke.edu/>. Those accepted into the program will be notified by July 1.

Applications for the University of Pittsburgh Training in Clinical Research Program are due by Mar. 1. Developed from a collaboration between Pitt and the Clinical Center, the program leads to a certificate in clinical research or a master of science in clinical research awarded by the University of Pittsburgh.

Unlike the NIH-Duke program initiated in 1998, the Pitt program is open to a wider audience, including Ph.D.'s and doctorally prepared pharmacists and nurses. Physicians and dentists are also eligible.

The training requires that students spend 8 weeks in residence at the University of Pittsburgh starting in July. Additional coursework for the program is offered at the Clinical Center via videoconferencing.

For more information, visit http://www.cc.nih.gov/cc/cc_pitt/index.html or send email to tcpr@imap.pitt.edu. Successful applicants will be notified by May 29. ■

Five Join NIAID Advisory Council

Five new members recently joined the National Advisory Allergy and Infectious Diseases Council. They are: Dr. Luis A. Diaz, professor and chairman of the department of dermatology at the University of North Carolina at Chapel Hill; Dr. J. Brooks Jackson, professor and chairman of the department of pathology at Johns Hopkins University Medical Institutions; Dr. Dorothy E. Lewis, professor of immunology at Baylor College of Medicine; Dr. Richard M. Locksley, chief of infectious diseases at the Howard Hughes Medical Institute at the University of California, San Francisco; and Dr. Margaret A. Liu, senior advisor in vaccinology at the Bill and Melinda Gates Foundation.

Diaz studies cutaneous autoimmunity. He has made important contributions in autoantibody-mediated disease in pemphigus and pemphigoid. Additionally, he is interested in medical education and patient care.

Jackson directs the clinical HIV laboratory at Johns Hopkins Hospital and has been involved in numerous clinical HIV therapeutic and prevention trials in the United States, Uganda and China.

Lewis is director of the core flow cytometry facility and director of the immunology core for the Center for AIDS Research at Baylor College of Medicine; she is interested in the immune response to HIV and the mechanisms responsible for failure to generate sufficient memory cells in most infected people.

Locksley's research investigates mechanisms by which T cells acquire their distinct effector functions and attempts to understand the dysregulation of effector function that occurs in a variety of infectious and inflammatory diseases.

Liu is a pioneer in the field of DNA vaccines; her research interests are in the field of immunology, in particular the generation of cellular immunity for viruses and cancer. ■



Dr. Anthony Fauci (r), NIAID director, welcomes new advisory council members (from l) Dr. Luis A. Diaz, Dr. Richard M. Locksley, Dr. J. Brooks Jackson, Dr. Margaret A. Liu and Dr. Dorothy E. Lewis.

Healthy Children Needed

NINDS is seeking healthy children, ages 5-17, to participate in a study about speech disorders. Your child may be eligible if he/she has normal speech and hearing, and English is the first language. Participation involves 4-5 outpatient visits. Compensation is provided. Call 496-9367. ■

Perception Study Needs Volunteers

The Uniformed Services University department of medical and clinical psychology needs healthy male and female volunteers, ages 18-80, to participate in a 2-hour study of perception. Payment is \$30. Call (301) 295-9679 to volunteer.

Earleen Elkins Dies, Former Review Chief

Dr. Earleen Elkins, who retired from NIH in 1996 after having served both NIDCD and NINCDS in extramural program leadership roles, died Jan. 26 in Ft. Myers, Fla.

"Earleen Elkins was a person of great energy who delighted in outstanding science and, especially, in encouraging young investigators," said Dr. James Battey, Jr., director of the National Institute on Deafness and Other Communication Disorders, as news of her death reached scientists meeting at the Association for Research in Otolaryngology (ARO) in St. Petersburg, Fla., and her former colleagues at NIH.



Dr. Earleen Elkins

Elkins had served as deputy director of the Division of Extramural Affairs and chief of the Scientific Review Branch at NIDCD after years on the staff of the then NINCDS. She had joined DHHS in 1976 after serving at the Department of the Army and at the Veterans Administration.

She was on the faculty of the department of hearing and speech sciences at the University of Maryland, where she taught audiology and statistical methods.

Barbara Sonies, chief of the oral motor function section and director of the oral pharyngeal function-ultrasound imaging lab at the Clinical Center, said of her former colleague, "She served as dissertation advisor and mentor to many appreciative graduate students and professionals."

Elkins had been honored by ARO several years ago with an Award of Merit. Among her many honors were the Hearing Research Award from the National Organization for Hearing Research and the E. Elkins Research Grant established by the American Academy of Otolaryngology Head and Neck Surgery in her honor.

Elkins served as mentor to many program and review professionals at NIH. She also took great pride in her husband, her children and their families, as well as in her three sisters who survive her.

She also took pride in her golf game. She was past president and member of the Golf Association at Highland Woods Country Club in Bonita Springs, Fla.

Elkins' family has asked that expressions of sympathy take the form of contributions to the Children's Inn at NIH. As one friend said, "I pictured her laughing and enjoying the course for at least another 20 years...it was just too soon and too sudden."

HRDD Class Offerings

The Human Resource Development Division supports the development of NIH human resources through consultation and provides training, career development programs and other services designed to enhance organizational performance. For more information call 496-6211 or visit <http://LearningSource.od.nih.gov>.

Foreign Travel	2/25, 26
IMPACT for Administrative and Professional Staff	2/26
Supervision: New Skills and New Challenges	2/26
Introduction to MS Outlook	2/26
IMPACT System for HR Staff	2/27
Fellowship Payment System	2/27
Professional Service Orders	2/27
Intermediate MS Access 2000	2/28
Fellowship Payment System Refresher	2/28
Domestic Travel	3/4, 5, 6
Supervising Former Peers	3/4
Advanced MS Word 2000	3/4
Speaking on the Job-Part II: Presenting Yourself	3/4, 5, 6
Leading Others: A Myers-Briggs Workshop	3/5
Communication and Negotiation for Women in Science	3/5, 7
The Leadership Edge	3/6
How to Give Constructive Feedback	3/6
Foreign Travel	3/7, 8
Intermediate MS Excel 2000	3/7
How to Plan and Run Productive Meetings	3/7
IMPAC II Grants Management	3/7
Purchase Card Training	3/8

CIT Computer Classes

All courses are on the NIH campus and are given without charge. For more information call 594-6248 or consult the training program's home page at <http://training.cit.nih.gov>.

Creating Presentations with PowerPoint 2001 for the Mac	2/21
Outlook 2000 Tips and Tricks	2/21
EHRP/PeopleSoft Hands-On Workshop for NIH Human Resources (HR) Staff	2/21
Avoiding Pitfalls in Statistical Analysis	2/22
Introduction to JavaScript Programming	2/22
SAS Programming Fundamentals I	2/25-26
Using Photoshop to Work with Scientific Images	2/26
BRMUG-Biomedical Researchers Macintosh User Group	2/26
Cost-Benefit Analysis	2/27
Meet Your PC-What's Inside the Box	2/27
KMIG-Knowledge Management Interest Group	2/27
Introduction to FileMaker Pro 5	2/28
The NIH Intranet Web Portal: An Overview of Technology and Content	2/28
SAS Programming Fundamentals II	3/4-5
XML Basics	3/4 - 4/8
Introduction to Programming	3/5-8
mAdb Basic Informatics	3/6
Data Visualization Using Microsoft Data Analyzer and MapPoint .NET	3/6

NCI Mourns Loss of Susan Sieber

By Margaret Vaughn

Dr. Susan Sieber, a 30-year veteran of the National Cancer Institute, died on Jan. 22 in Rockville of breast cancer. She was 59.

The sad news left her many friends and colleagues across the NIH campus remembering her extraordinary contributions to the institute over the past three decades.

"She was a graceful and extraordinarily gracious person," said Dr. John Weinstein, one of Sieber's research colleagues at NCI. "Key to her success was a wonderfully receptive nature and a generosity of spirit. It stood her well in her activities as a researcher and in administration."

Sieber joined NCI as a staff fellow in 1971 after completing her pharmacology Ph.D. at George Washington University. In 1980, she was appointed acting chief of the Laboratory of Chemical Pharmacology.

Over the next two decades, however, her interest in developmental toxicology, biochemical epidemiology and cancer in women and special populations propelled her to leading roles in a wide variety of NCI offices including the Division of Cancer Control and Populations Science and the Division of Cancer Epidemiology and Genetics.

Sieber is remembered for her ability to build bridges between scientists with differing specialties and outlooks, said Dr. Aaron Blair, Occupational Epidemiology Branch chief of the Division of Epidemiology and Genetics.

"Susan was very good at pulling people together from disparate backgrounds and getting them to think about a common topic," he said. "She could reach out and make them feel integrated into the project."

Sieber chaired and served on numerous scientific boards and working groups including the U.S. Army Breast Cancer Research Program integration panel, the board of directors of the Reproduction Toxicology Center and the NIH interagency working group on breast and gynecologic cancer. She also taught in the NIH graduate program and wrote or coauthored 76 scientific papers.

But it was her personal commitment to fighting breast cancer through outreach to its many victims that is remembered in places as remote as Triana, Alabama.

Sieber was instrumental in establishing a study there in the mid-1990s that examined the connection



Dr. Susan Sieber

between environmental contaminants such as DDT and unusually high incidences of breast cancer, said Dr. Jane Cash, professor of nursing at Jacksonville State University.

"Triana was poor, rural and underserved," Cash said. "Susan would fly down for meetings and obviously enjoyed meeting and helping the people. She took a personal, as well as professional, interest. She really wanted to make a difference."

Sieber's influence on the women in Triana continues even today, Cash noted. "The women in that community were empowered and continue to support each other—Susan was pivotal in that."

After serving as associate director of special projects in the late 1990s, Sieber's skills in cancer communications led to an appointment as director of NCI's Office of Communications in 2000. She retired from that position late in 2001.

Survivors include her parents and two brothers. Her husband of 17 years, Dr. Sergio Fabro, died in 1988. ■

Software Vendor Day, Feb. 28

If you're worried about your next software acquisition, worry no more—let CIT's software distribution project (SDP) help you uncover the mysteries of software acquisition. CIT is sponsoring a Vendor Day on Thursday, Feb. 28 from 8 a.m. to 4 p.m. The atrium space at the Natcher Conference Center will be filled with exhibitors.

Vendors include Absolute, Adobe, Apple,BindView, CDW-G, Dataviz, FileMaker, GTSI, Microsoft, Network Associates, Novell and WebTrends. Vendor Day is open to all NIH and DHHS employees.

CIT's SDP saves nearly \$10 million annually. It provides major software titles to more than 40,000 customers from NIH and DHHS.

Vendor Day will provide an open forum where you can meet with vendor representatives. In addition to exhibits, selected vendors will formally present their products. Visit http://sdp.cit.nih.gov/information/vendor_day.asp for updated vendor and event information.

Blood Samples Needed

An NIH study is recruiting healthy African-American, Taiwanese and Japanese adults to donate 1 teaspoon of blood. The samples will be used to test for a platelet membrane glycoprotein (CD36) that is absent from the platelets of a small percentage of individuals from these populations. To be eligible you must be 18 years of age or older. Compensation will be provided. Those interested should contact D.J. McCloskey, 496-5150. ■

Metabolism Study Recruits

Nonsmoking, premenopausal female volunteers without major medical problems (normal weight and overweight, ages 18 and older) are sought for a study on eating and metabolism. Participation requires: keeping a 1-week eating diary and 2 visits (a total of 4-6 hours) including a sub-maximal exercise test, assessment of body composition and metabolic rate. Participants will receive \$50, a group lecture on eating and weight management, and feedback on their food-intake, body composition and metabolic rate. For more information call Teresa Hughes at the Uniformed Services University of the Health Sciences, (301) 295-1498.



Dr. Anne Willoughby, who has led the Pediatric, Adolescent and Maternal AIDS Branch at NICHD for the last 13 years, has been appointed director of the Center for Research for Mothers and Children at the institute. She began her career in 1984 at NICHD, conducting research on the effects of chloride deficient formula on child development. She has spent the last 13 years enhancing knowledge about HIV/AIDS in mothers and children. In her new position, Willoughby will have the opportunity to tackle the numerous health issues facing mothers and children. Her efforts will be focused on low birth weight infants, developmental disabilities, learning disabilities, birth defects, growth and nutrition, HIV/AIDS, and the effects of racial and ethnic disparities on mothers and children.

New Computer Classes Available

The CIT Computer Training program has begun its spring 2002 term of classes. All classes are offered without charge and registration is now open. CIT classes are designed for scientists, computer support staff and end users. Many new offerings join returning favorites.

For researchers doing sequence analysis, two new classes are available. "High-Volume, High-Speed Sequence Analysis on the Biowulf Supercluster" will examine options available for NIH researchers needing to do large-scale projects.

"Homology Modeling with GeneMine" will study a free program for sequence analysis and visualization that makes use of analysis servers across the Internet to filter for meaningful results.

Scientists analyzing microarray data also have two new options. "Microarray Data Analysis Using S-Plus: From Quality Control to Discovery" will examine ways the S-Plus statistical package can be used to control data quality, normalize data and do analysis and visualization.

The new "Statistical Analysis of Microarray Data" will provide an overview of statistical issues that arise in the design and analysis of microarray studies followed by a hands-on demonstration of BRB Array Tools. It is a followup to the continuing "mADB Basic Informatics" class.

Finally, scientists looking to create their first web pages can attend "Practical Web Page Development for NIH Researchers." This class covers material similar to the existing "Introduction to HTML" class but with a focus on pages to be used for small-scale scientific collaboration.

Blackberry wireless handheld devices have become popular at NIH. "Blackberry Tips and Tricks" will help users understand and optimize their capabilities.

As computer security concerns continue to increase, two more classes have been added to the many security offerings. "Basic Security Principles" is intended to introduce a non-technical user to the principles of how to keep data secure at NIH. "Building a Secure Home Network" is a hands-on class that will include discussion of CIT's remote access solutions and evaluation of various software packages and hardware that supports home networks.

For FileMaker users, "Advanced FileMaker Pro 5" has joined the existing Introduction and Intermediate classes. Students will learn to create an integrated database system that will use advanced automation, word processing and navigation features. The hands-on lab exercises for these courses will be available on both PCs and Macs.

In response to many student requests, the new "XML Basics" will provide a hands-on class for six sessions. It will cover the basics of XML and DTD

syntax as well as how XML documents can be transformed using XSL style sheets.

Microsoft is bringing demonstrations of many of its newer products. "Overview of Office X for the Mac" includes a Macintosh specialist who will provide a look at this first version of Office to be native to the OS X operating system. Microsoft will also present: "Data Visualization Using Microsoft Data Analyzer and MapPoint .NET," "Software Construction Using Microsoft Component Systems," and "Enterprise Project Management Using Microsoft Project 2002."

As always, classes are available without charge to employees and other users of NIH computing facilities. To obtain full course information or to register for classes, visit <http://training.cit.nih.gov/>. Or call 594-6248 (GOCIT) if you wish to discuss course registration, teaching a class or other training issues. ■

Wednesday Afternoon Lectures

The Wednesday Afternoon Lecture series—held on its namesake day at 3 p.m. in Masur Auditorium, Bldg. 10—features Dr. Aravinda Chakravarti on Feb. 27, who will give a talk on the subject "Genetic Architecture of Complex Disease: Simple or Complex?" Chakravarti is Henry J. Knott professor and director, McKusick-Nathans Institute for Genetic Medicine, Johns Hopkins University School of Medicine.

On Mar. 6, Dr. Ann M. Graybiel, Walter A. Rosenblith professor of neuroscience, department of brain and cognitive science, MIT, will discuss "Neural Mechanisms of Habit Formation; Plasticity in Cortico-Basal Ganglia Loops."

For more information or for reasonable accommodation, call Hilda Madine, 594-5595.

Have Panic Disorder?

NIMH is seeking medically healthy volunteers ages 18-50 who suffer from panic disorder to participate in research studies that include free evaluations and brain imaging (compensation provided) and/or medication treatment. Participants should not be taking any psychiatric medications currently. Call 496-5645 (TTY 1-866-411-1010). ■

Volunteers Needed

An NIH study is seeking individuals currently taking an anti-depressant (Wellbutrin). Four tablespoons of blood will be taken for evaluation. Compensation is provided. Call Donna Jo McCloskey for more information and to schedule an appointment, 496-5150. ■