

THE NIH RECORD

Still The Second Best Thing About Payday

Blood Supply Largely Safe, But More Needed

By Rich McManus

As recently as the mid-seventies, about the time the United States adopted a national blood policy (1973), a patient requiring blood transfusion for an operation at the Clinical Center had a one in three chance of contracting hepatitis from the transfusion. Today, thanks to improvements in screening donors and their blood, the rate of transfusion-associated hepatitis at NIH has dropped to virtually nothing.

So reported Dr. Harvey Klein, chief of the Clinical Center's department of transfusion medicine, at a Grand Rounds presentation Mar. 8 on the supply, safety and adequacy of the nation's blood reserve. Klein, who joined DTM in 1973 and has been department chief since 1984, surveyed the horizon of risks associated with blood transfusion, and found most of them on the down-

SEE BLOOD SUPPLY, PAGE 4

A Night of W;t and Wisdom

Play Raises End-of-Life Issues

By Linda Cook

An educational event to raise awareness about the need for end-of-life research, "An Evening of *W;t* and Wisdom: The Science of Care and Compassion at the End of Life," was held at the Kennedy Center on Mar. 9. The focus of the event was the Pulitzer Prize-winning play *W;t* and included a pre-play reception and a post-play question-and-answer forum. Sponsored by the Coalition for End-of-Life Research and Care, with the National Institute of Nursing Research, the sold-out event achieved its goal. Actors, speakers and attendees, which included multidisciplinary researchers and clinicians and the public, pooled their knowledge and explored the concerns that affect patients, families and health-

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Infection Rates Rising in Women

HIV/AIDS Epidemic 'Still Advancing,' Panel Warns

By Carla Garnett

Even with all the weapons—heightened public awareness campaigns, safe sex advisories, needle exchange programs, treatments such as zidovudine (AZT), protease inhibitor "cocktails" and most recently, highly active antiretroviral therapy (HAART)—deployed against the HIV/AIDS epidemic in two decades, the disease is still winning, according to panelists at a recent women's health seminar. Further, they point out, the epidemic's relentless advance is no more increasingly evident than in the world's women and children.



Dr. Neal Nathanson talks about the AIDS epidemic.

"The epidemic abroad is quantitatively so much larger than the one we face here...[the epidemic] is particularly intense in Africa," said Dr. Neal Nathanson, NIH associate director for

AIDS research and one of four presenters at a recent seminar

SEE EPIDEMIC ADVANCING, PAGE 6

Real-Life Lifesaver Still Saving Lives

Prolific NIH Blood Donor Goes to Capitol Hill

By Carla Garnett

When Congress needed a role model for its annual blood drive competition, who did they call? When U.S. Surgeon General David Satcher wanted to team up to tape public service announcements on the importance of blood donation, who did he tag? Howard Drew, the same man who has donated more than 200 units of blood over the last 50 years and whose phone number might as well be on speed dial at the Clinical Center's department of transfusion medicine. Drew is a former reference librarian



NIH Hall of Fame blood donor Howard Drew (l) teams up with U.S. Surgeon General David Satcher to promote blood donation nationwide.

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LETTERS TO THE EDITOR



Dear Editor,

I read with interest the recent article in the 3/21/00 issue regarding initiatives to protect participants in gene therapy trials.

At a Cold Spring Harbor Genome Meeting in May 1997, I listened to a presentation during the ELSI (Ethical, Legal and Social Implications) session which proposed that the term "genetic therapy" be abandoned as misleading. In my view, this has been shown in recent events to have been correct. It is important research. It is NOT therapy and should not be described as such. It is past time for the many workers in this field and the lay and scientific press to cease using the term "genetic therapy."

Jim Nagle, NINDS

Calling Computer Users in Offices

Individuals working full time and using a computer keyboard a minimum of 3-4 hours a day are needed for a research study on the role of workstyle in occupational health. Volunteers with and without upper extremity symptoms (fingers, hands, wrists, forearms, elbows, shoulders and neck) are needed to participate in 2-hour focus group interviews. Focus groups are being conducted by researchers at Georgetown University Medical Center. Compensation will be provided and groups will be scheduled at convenient times and locations. For more information, call Stacy Chambers at (202) 687-2392.

'Faces & Phases of Life' Seminars

The NIH Work and Family Life Center and the NIH Employee Assistance Program present the following free seminars. Teleconferencing is available to most locations on request. Contact the WFLC, 435-1619 or TTY/TDD 480-0690, to preregister to attend or to arrange teleconferencing for your IC. Videotapes of the seminars can be checked out from the WFLC Work/Life Resource Library. Sign language interpretation is available. For reasonable accommodation, call at least 48 hours prior to the seminar. More information is available on WFLC web site at <http://wflc.od.nih.gov>.

Transition Management: Coping With Workplace Change

Apr. 4, noon-1 p.m., 31/6C6

Parenting Styles That Work With Teens

Apr. 11, noon-1:30 p.m., 31/6C6

Understanding Alzheimer's Disease

Apr. 18, noon-1:30 p.m., 31/6C6

Montgomery College

Apr. 19, 11:30 a.m.-1 p.m., 31/6C10

Note: Call Sally Murray to preregister at 496-6211.

Preparing Federal Application Materials

Apr. 25, 11 a.m.-1 p.m., 31/6C6 ■

Does Alcohol Use Affect You?

The NIH Employee Assistance Program will present a 3-part series on alcohol use, abuse and related problems called "Happy Hour, from Cheers to Tears." It will be held on Wednesdays Apr. 19, 26 and May 3 from noon to 1 p.m. in the Little Theatre, Bldg. 10. The kick-off session will be an overall discussion of the nature of alcohol misuse in general, from workplace to home-base. Subsequent sessions will assist in guiding the participant toward recognition of the problem in self, loved ones, friends or coworkers and in identifying sources of help to address the problem. For more details call the Employee Assistance Program at 496-3164, or visit its web site at <http://www.nih.gov/od/ors/ds/page2/oms/eap.htm>. ■

NIH'ers Support Their Own Charities



George Williams (l), director of the Design, Construction and Alteration Branch, ORS, donates \$750 from the Year of Sports Giveaway Program. Jay Hull was the winner of tickets to all area sports programs, and Randy Schools (r), R&W president, accepted the check on behalf of the NIH-affiliated charities (including Friends of the Clinical Center, Special Love, Inc./Camp Fantastic and the Children's Inn).



Members of the NIH Community Orchestra donate proceeds from their yearly concerts to NIH charities. Shown are orchestra representatives (from l) Jerry Danoff of the Clinical Center; Harold Seifried of NCI; Schools of R&W; Gary Daum, conductor of the orchestra; and Steve Soroka of CIT. The orchestra is comprised of NIH employees and their friends.

N I H R E C O R D

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Discovery of Taste Receptors May Make Bitter a Bygone Taste

It's an old axiom that in life we have to "take the bitter with the sweet." A recent study has shown that humans, as well as rodents, are well equipped to do just that. Scientists have discovered a new family of taste receptors (T2Rs) that may comprise as many as 80 different members, which together help detect different forms of bitter. Why so many? In nature, bitter comes in many shapes, most often associated with poisons, so broad recognition of this taste perception can be critical to an animal's survival. Now that the molecular structure of these receptors is known, scientists may be able to use this knowledge to take the bite out of bitter.

Dr. Nicholas Ryba from the National Institute of Dental and Craniofacial Research and Dr. Charles Zuker from the Howard Hughes Medical Institute and the University of California at San Diego have established a long-term collaboration to investigate the sense of taste. Last year, their groups reported the identification of the first two strong candidate taste receptors: TR1 and TR2. Their work describing and characterizing the new T2R taste receptors is reported in two articles in the Mar. 17 issue of *Cell*.

According to Ryba, "We now have the means to really start to investigate how taste works, not just in the tongue but also what happens in the brain." Dr. Mark Hoon of NIDCR, a coauthor of the study, adds, "These results significantly enhance our understanding of bitter taste and provide clues about how the sensation of bitter might protect animals from many poisons." Zuker and Ryba are continuing their studies not only to dissect the basis of taste perception but also to identify compounds that might be used to modify the human sensation of bitter.—Wayne Little ■

Gene Tracking Follows Cells from Embryo to Adult

In a sense, all teeth can be considered wisdom teeth if their cells of origin are the determining factor. Scientists have developed a sophisticated genetic tracking system that allows them to follow the migration of cells as they stream from the embryonic mouse brain to the developing body, including the primordial jaw where they contribute to the formation of teeth and supporting structures. This is the first time a group of embryonic cells has been "tagged" and followed throughout development to their final destiny.

The research was a collaborative effort of several institutions led by Dr. Yang Chai from the University of Southern California. The study, which appeared in the Mar. 21 issue of *Development*, was supported in part by the National Institute of Dental and Craniofacial Research.

"This technology allows us to closely follow an important group of cells that contribute not only to formation of the teeth and other craniofacial structures, but also to parts of the developing cardiovascular system," said Chai. "We will soon be able to look at animal models for a variety of human genetic disorders and observe in minute detail the effects on this key cell population. Likewise, we will be able to scrutinize corrective measures such as gene therapy."—Wayne Little ■

Compounds May Be Useful Against Osteoarthritis

A systematic analysis of clinical trials on glucosamine and chondroitin sulfate for treating osteoarthritis (OA) has shown that these compounds may have some efficacy against the symptoms of this most common form of arthritis, in spite of problems with trial methodologies and possible biases. The study, by Dr. Timothy E. McAlindon and colleagues at Boston University School of Medicine, published in the Mar. 15 issue of the *Journal of the American Medical Association*, recommends that additional, rigorous, independent studies be done of these compounds to determine their true efficacy and usefulness.

"About 21 million adults in the United States have OA," said Dr. Stephen Katz, director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, which funded the study and has helped launch a major clinical trial on the compounds in OA, along with the National Center for Complementary and Alternative Medicine. "Effective treatments are key to improving the quality of life of Americans affected by this common disorder."

OA, also called degenerative joint disease, is caused by the breakdown of cartilage, which cushions the ends of bones within the joint. It is characterized by pain, joint damage and limited motion. It generally occurs later in life, and most commonly affects the hands and large weight-bearing joints such as the knees and hips.

The Boston researchers point out that glucosamine and chondroitin sulfate have received significant media attention and have been used in Europe for OA for over 10 years. The researchers say physicians in the United States and the United Kingdom have been skeptical about these products, probably because of well-founded concerns about the quality of scientific trials conducted to test them. Glucosamine and chondroitin sulfate, which are sold in the U.S. as dietary supplements, are natural substances found in and around the cells of cartilage. Researchers think these substances may help in the repair and maintenance of cartilage.—Connie Raab and Kelli Carrington ■



Dr. Stephen I. Katz, NIAMS director and NCI Dermatology Branch chief, was awarded an American Academy of Dermatology (AAD) Presidential Citation on Mar. 13, "for leadership and vision in enhancing international dermatologic relationships and advancing the quality of worldwide dermatologic care." The award was given at the annual AAD meeting at the Moscone Convention Center, San Francisco.

BLOOD SUPPLY, CONTINUED FROM PAGE 1

sweep.

Hepatitis A is very rarely passed along by blood transfusion; hepatitis B is detectable by two tests, however there is a "window" during which the virus can't be found—a new vaccine for hepatitis B should assure that this disease, too, becomes more rare; hepatitis C poses a far lower risk by blood transfusion than it did in the past. "Less than 5 percent of new infections are associated with transfusion," Klein said. Some 200,000 new cases of the illness are, nevertheless, diagnosed each year.

Turning to HIV, Klein noted that 1 in 300 Americans carries the virus. Chillingly, 90 percent of the recipients of HIV-contaminated blood later become infected. Less than 40 HIV infections via transfusion have occurred in the United States since 1985, Klein said. With the reduction of the number of high-risk donors (by pre-donation histories taken by blood bank personnel) and with current sensitive screening tests (of which there are two), the risk is approaching 1 in 1 million, or about that of being struck by lightning, he explained. Similarly, the risk of acquiring hepatitis C by transfusion equates roughly to that of being killed in a train accident in the next year.

Klein then looked at other possible blood contaminants such as retroviruses, parasites, prions and emerging viruses. Malaria, he said, is by far the most important transfusion-transmitted illness on a worldwide basis, but is relatively rare in the U.S. Only 103 cases were reported in the period 1958-1998, making the odds of acquiring malaria from transfusion about 1 in 4 million. However, the malaria parasite can persist in blood for around 40 years, so the possibility of its entering the blood supply is real. "We don't often think about it as one of our risks," Klein observed, "but we have to remain vigilant because the mosquito vector is present in the U.S. We do get 'imported' cases, and it could become a larger problem for transfusion because there are no good screening tests."

Also unusual, but not entirely unknown, are cases of rare strains of HIV that can pass into the blood supply. Klein said a new test that recognizes nucleic acid sequences in the AIDS virus (the NAT test) will help further expunge this risk when it becomes available in a year or so. "We are currently using this NAT technology on an experimental basis on all blood collected at NIH," he said. "I expect the test to be licensed for use across the country within the next year, for both HIV and HCV (hepatitis C virus)."

Interestingly, Britain is now in the throes of concern about the possibility of "mad cow" disease tainting that nation's blood supply. As of March 1999, some 39 people—many of them quite young—have died from this disease. "(The British) are where we once were with respect to fears of HIV

in our blood supply," said Klein. However, no data support the hypothesis that bovine spongiform encephalitis—mad cow disease's less daunting name—is transmissible by blood. Even so, Canada has barred blood donations by recent visitors to the U.K. And the Food and Drug Administration has recommended that anyone who spent a total of 6 months in Britain between the years 1980 and 1996 refrain from donating; this translates to about 2 percent of the donor population. "More and more people are being told that their blood is 'bouncing' at blood banks," Klein observed.

Creutzfeldt-Jakob disease—another illness laid to the mysterious workings of a pathogen called a "prion"—doesn't seem to be associated with transfusion, either, Klein stated. CJD, which affects about 1 in 1 million Americans, is screened for, however, using family history information taken at blood banks. Klein cautioned that, since CJD has such a long incubation period—as much as 40 or more years—it is not currently possible to prove that there is no risk of its transmission via transfusion.

Klein emphasized that with CJD and mad cow disease, the disease risk is purely theoretical; no science suggests they threaten the blood supply. "While we need to remain vigilant and caution is certainly important, we must not make well-intended decisions that have severe implications for the supply of blood. Continually eliminating apparently healthy donors for minimal theoretical safety risks is ill-advised because it jeopardizes supply. Supplies are low across the U.S., as well as in our area. Three weeks ago, a young woman who was bleeding in the operating room at Fairfax Hospital could not get O-negative blood from the regional supplier. Fortunately, NIH had 2 units on its shelf."

NIH's are by now used to getting urgent emails from the NIH Blood Bank asking for donations of unusual types, and they are likely to continue. Klein reported that, nationally, red cell collection is down markedly, and that 8.6 percent of U.S. hospitals report canceling surgery for 1 or more days due to lapses in the blood supply.

"We do have to start being seriously concerned about the availability of blood," he said. "(Hospitals) have to have the right (blood) group at the right time."

Klein concluded with a dual message: "Blood is not entirely risk free, but it is very safe." With some 16 million units of blood and blood components transfused annually in the U.S., he explained, "A zero risk is unrealistic. We also need to protect and increase our donor base and frequency."

In cases where you can donate blood for yourself ahead of time, that is to be preferred, he said. But even when circumstances are such that you can't, you are still in pretty good hands. ■

Children Needed for Study

The Pediatrics and Developmental Neuropsychiatry Branch, NIMH, is studying how the brain controls finger movements, and needs normal kids (or a child with a diagnosis of attention deficit and hyperactivity disorder) ages 6-13. They must be available for 3 hours for a noninvasive study that includes neurological examination, transcranial magnetic stimulation, EMG using surface electrodes and ADHD assessment. Pay is provided. If interested, call Dr. Marjorie Garvey, 496-5323, for more information.

Arthritis Educators Score High with Patients

Arthritis educators can provide a meaningful boost to traditional care for patients with rheumatic diseases, according to a new study reported in *Arthritis Care and Research*. Teaching and support by trained educators has been proven to have a positive impact on the knowledge and satisfaction with services for patients with arthritis visiting rheumatology clinics.

"People with arthritis are often dissatisfied with their care. We have shown that arthritis patient educators can be a useful addition to traditional rheumatology care," said coauthor Dr. Peter Lipsky, NIAMS scientific director. "We now know for certain that patient education positively affects patient knowledge, disease management and satisfaction with clinic services."

In the study carried out at the University of Texas Southwestern Medical Center in Dallas, one group of patients with arthritis was randomly assigned to an arthritis patient educator as well as standard rheumatologic care. A control group was assigned to receive only the standard care. Both groups completed standard assessment tests.

The results showed that the patients who received the intervention displayed more overall knowledge about their disease than patients who did not. Of this group, 88.5 percent rated the arthritis patient educators "good" or "excellent;" 69 percent found the educators helpful; and 58 percent requested further interactions with the educators. Test group patients were able to name more sources of arthritis information and self-help aids.

Because arthritis is the most costly, chronic and common disease known, the goal of arthritis management has been to minimize pain, inflammation, disability and the psychosocial changes associated with the disease. Currently, arthritis affects over 40 million (15 percent) of the American population, and the number is expected to increase to nearly 20 percent (60 million) by 2020. It is the leading cause of disability in Americans over 65.—Janet Howard ■

Female Volunteers Needed

The Behavioral Endocrinology Branch, NIMH, is seeking female volunteers ages 40-55 to participate in a 6-month study of the effects of aging and reproductive hormones on measures of cerebral activity, blood flow and stress hormone production. Volunteers must have regular menstrual cycles with no changes in mood in relationship to menses, be free of medical illnesses and not taking any hormones or medication on a regular basis. Payment will be in accordance with the duration of each visit and the type of protocol. For more information, call Linda Simpson-St. Clair, 496-9576. ■



Janice Hedetniemi, director, Office of Community Liaison, recently accepted the Montgomery County Civic Federation Community Hero Award on behalf of her office from federation president Dr. Jorge L. Ribas. The award recognizes contributions to the quality of county life and was won on the basis of NIH's commitment to create a partnership with surrounding neighborhoods. Ribas said NIH's establishment of "good neighbor" policies and its fostering of constructive dialogue and mutual respect have made NIH a model among federal agencies in the metropolitan area. Hedetniemi also recently learned that she has been selected for the Leadership Maryland Class of 2000; she is one of 52 statewide leaders picked to participate in an 8-month program acquainting rising leaders from the public and private sectors with issues facing the state of Maryland and its regions.

Gene Therapy Restores Muscle Function in Dystrophic Hamsters

Scientists supported by NIAMS have used gene therapy to restore muscle function in a hamster model of limb-girdle muscular dystrophy (LGMD), a group of degenerative muscular diseases caused by mutations in the gene for the protein δ -sarcoglycan. The work has implications for treating the human forms of this and other muscular dystrophies.

A group of investigators led by NIAMS grantee Dr. Xiao Xiao at the University of Pittsburgh injected a virus vector (adeno-associated virus, or AAV) bearing corrected copies of the gene into a leg muscle of the hamster LGMD model. The result was over 97 percent recovery in muscle strength in the dystrophic animals compared with normal hamsters. Treated animals also regained normal muscle weight and size and showed improvement in muscle cell condition. Furthermore, the treatment conferred protection from muscle loss.

"This work, coupled with other recent advances, signals a brighter day for those with many forms of muscular dystrophy," said NIAMS director Dr. Stephen Katz. "Animal model research like this points to gene therapy as a likely candidate for treating some human muscle diseases."

The study, according to the authors, "is the first report of successful functional rescue of an entire muscle after AAV-mediated gene delivery." But since muscle is one of the larger human organs, they add, successful transfer of this technology to patients will depend in part on producing and delivering large amounts of the vector safely.—Ray Fleming ■

NIH'ers Address Personnel Conference

The International Personnel Management Association of Montgomery County will hold its annual spring training and development conference at the Bethesda Hyatt on Tuesday, Apr. 11. The theme is the "Art of Human Resource Management." The keynote address will be given by Dr. Ruth Kirschstein, acting NIH director; special guest lunch speaker will be Stephen Benowitz, director, NIH Office of Human Resources. For more information or to register for the conference, see the web site at <http://137.187.156.2/ipma/ipma2k.html> or call Joan Patton at 402-2825.

EPIDEMIC ADVANCING, CONTINUED FROM PAGE 1

sponsored by the Office of Research on Women's Health.

State of the Epidemic

In his overview, "AIDS in Women: Epidemiology and Control in Africa, the Third World, and the United States," he said the estimated number of people living with HIV/AIDS by the end of 1999 was 23.3 million in sub-Saharan Africa and 920,000 in the United States. In Africa, prevalence and number of new cases are both increasing each year. In the U.S., 800,000 people are estimated to be living with HIV/AIDS; 300,000 of those can be considered to have AIDS already, according to Centers for Disease Control and Prevention classifications.

"When an epidemic becomes this big," Nathanson said, "usually it levels out and becomes endemic, but in fact the epidemic is still advancing...We are not getting on top of this epidemic from a public health point of view."

Another thing about the U.S. epidemic is that it has changed radically in terms of the population that is affected, Nathanson added, noting that heterosexual transmission is the primary mode of transmission in developing countries. "In the past in the U.S., it has been much more of a disease among men than women, although that's rapidly changing. It has become much more an epidemic of minorities, moving from a little more than a third to at least two-thirds of the population, and much more of a problem of women," who now account for at least one quarter of the epidemic and that number is rising.

"The good news is that HAART is quite effective," he said, "resulting in a remarkable drop in the death rate, which is now plateaued at 50 percent of the peak—20,000 [deaths] in the last year, as opposed to the 40,000 a few years back."

He mentioned the epidemic's dramatic impact in Africa. Life expectancy—which had been improving—in sub-Saharan Africa has plummeted and "this is entirely due to the AIDS epidemic," Nathanson continued.

He did have some relatively good news from Uganda: A combination of social marketing, fear and concern stemming from the very high incidence of deaths and infections, and an acknowledgement that there is a lack of treatment, have all led to some safer sex practices, a reduction in partners, an older age of beginning sexual activity, and more use of condoms.

"As a result," he concluded, "there's been a rather remarkable drop in prevalence. That's a very important sentinel. [It indicates] there are ways one can put the brakes on the epidemic, even in countries with limited resources."

Still, he said, a much higher proportion of new

infections and existing infections in Africa are among babies and young children. Postpartum infection is still high there, as well as a considerable amount of transmission via breastfeeding.

Preventing Mother to Child Infection

Taking up where Nathanson's talk left off, a firsthand account of "Recent Advances in the Prevention of HIV Perinatal Transmission" was



Dr. J. Brooks Jackson

offered by Dr. J. Brooks Jackson, professor and vice chair of pathology for clinical affairs at Johns Hopkins, who has spent 10 years conducting clinical prevention studies in Uganda.

The substantial progress made in preventing perinatal transmission by the United States paved the way for the recent successes in developing countries, he said. The number of HIV-infected women who deliver babies in the U.S. every year has been fairly steady at between 6,000 and 7,000 per year. Over the years, with the use of AZT and now combination therapy, the number of perinatally acquired HIV cases has dropped considerably from about 1,500 per year to "probably less than 300 infants born in 1999 with HIV," Jackson said. In contrast, an estimated 700,000 infants in developing nations will be infected with HIV by their mothers during delivery; the number of babies infected rises even further when counting transmissions via breastfeeding.

Although most of the preventive regimens used in this country are far too expensive—about \$800 per mother/child for AZT, for example—to be adopted by developing nations, researchers supported by NIH and working in Uganda have been able to produce measurable results with other preventive therapies such as nevirapine—a single dose of which costs \$4 for each mother and each child, according to Jackson.

"While very successful here," he explained, "it's very difficult for governments in developing countries to be able to afford [an \$800 regimen], where healthcare expenditures are typically \$3 to \$10 per person."

Saying that the search must continue for alternative therapies, he outlined six requirements for new treatments: they must be safe, feasible, simple, efficacious, inexpensive, and able to be delivered peripartum (when most transmissions occur).

Jackson concluded by reporting non-cost related obstacles to getting the therapy to pregnant women in some parts of Africa, including slowness of governments to license and distribute the drug;

ignorance about the drug's benefits; and requirements that women first undergo testing and counseling, which is more expensive than the drug regimen.

"We think the nevirapine is safe and will be effective in preventing perinatal transmission," Jackson said, "and it is deliverable in sub-Saharan Africa and other resource-poor settings, but it does need to be translated into public health policy."

'Treatment in the Real World'

Dr. Victoria Cargill of NIH's Office of AIDS Research discussed "Treatment Issues and Challenges in Women," bringing firsthand experience from closer to home—inner city Cleveland.

"There certainly have been gains in the epidemic," she began, "however, the survival advantage has not been as profound in certain communities, particularly communities of color. Drug resistance continues to be a real consequence of treatment. Being compliant with one's medication continues to be a significant challenge, and there are major gaps in medication access."



Dr. Victoria Cargill

PHOTOS: JOHN CRAWFORD

Explaining that "HIV in women reflects not just one epidemic, but overlapping epidemics—epidemics of sexually transmitted diseases, alcohol and drug use, poverty and violence," Cargill explored several practical concerns often overlooked: some women's lack of knowledge about available treatments, their sometimes limited access to care, a mistrust of the medical establishment, and the competing needs of a woman's family and home life.

To illustrate her point about effective caregivers having to know a woman's life circumstances as well as her HIV status—or what she termed "survival collides with HAART: treatment in the real world"—Cargill described three HIV-positive women she had seen in her practice: A 52-year-old African American intravenous drug user addicted to heroin and crack cocaine, who—in order to support her drug habit—routinely fenced the hospital supplies she was prescribed and who had been subsequently dismissed from five previous practices; a 38-year-old Latina who had four daughters—three of them already diagnosed with HIV—and an abusive partner, was found to be 6 weeks pregnant and without money for housing; and a 15-year-old juvenile delinquent with a history of 10 sexually transmitted disease episodes in the last 2 years who claimed, upon being informed of her HIV-positive status, "I don't need no damn drugs."

In conclusion, Cargill shared several lessons she

has learned from treating such women: Learn to accept a less-than-perfect solution, assume nothing, and above all, know and respect your patient's needs.

"Therapy in this setting requires a lot of creativity," she said. "We have to be a partner with our patient. What may be top on my list is starting therapy; what may be top on her list is having housing and food for her children. We have to meet in the middle somewhere."

'Stealthy Prevention' Needed

Finally, Dr. Zeda Rosenberg, scientific director of the NIAID-funded HIV Prevention Trials Network at Family Health International, offered insight into the basic mechanics of HIV transmission in her presentation, "Approaches to Preventing HIV in Women."

Focusing on female-initiated prevention strategies, she said, there is a strong rationale for developing, for example, a topical microbicide that is both biodiffusible and bioadhesive—able to reach the "mountains and valleys" within the vagina, and stay in place during sex. It's also important, she noted, that whatever preventive is developed not interrupt the various natural defense systems of the vagina.

Acknowledging that scientists still are not sure exactly where in the female genital tract HIV transmission occurs, she said it is important that



Dr. Zeda Rosenberg

researchers designing prevention methods for women consider the intricacies of the female anatomy. Somehow, Rosenberg explained, HIV manages to get past the natural defense mechanisms within the vagina.

Agreeing with Cargill, Rosenberg said to stem transmission in women

effectively, developers must consider the circumstances of women's lives.

"Most women are infected by their primary partner," she explained, "and male condoms are less likely to be used during these encounters." In addition many women face a high prevalence of nonconsensual sex, and sex with nonmonogamous partners. Therefore, a stealthy prevention method needs to be developed so women can use it without informing their partners.

In response to a question about how to reach the seemingly unreachable women who are needed to test new therapies, Rosenberg gave advice that could summarize the seminar: "Don't do business as usual. You have to provide transportation. You have to provide childcare. We have recruiters on the streets at 2 in the morning. You don't wait for these women to come to you." ■

Travel, Weekend Getaway Expo

The NIH R&W is sponsoring a Travel and Weekend Getaway Exposition on Tuesday, Apr. 4 between 10 a.m. and 2 p.m. in Bldg. 10's Visitor Information Center. Door prizes will be available from many participating companies, including weekend getaways, mini-vacation tickets to special events, amusement park passes and more. Grand prize is a 4-day, 3-night Bahamas cruise. Representatives from hotels, resorts and area attractions will be on hand. Admission is free.

PROLIFIC DONOR, CONTINUED FROM PAGE 1

at the National Library of Medicine and the first inductee in the NIH blood donor Hall of Fame.

"I received blood in World War II," Drew explains, "and I realized the importance of blood donation. Later, while still serving in the Army, I decided to give back. I've been donating regularly since then."

So committed a donor is he that when DTM got a frantic call early this year for the name of a blood donor who might be willing to stump for the cause at an event on Capitol Hill, the first name DTM provided was Drew's. Apparently a donor scheduled to appear at the second annual "Fight for Life" congressional blood drive challenge had to cancel and on the day before the event, organizers at the American Association of Blood Banks were seeking a last-minute substitute. In rode Drew to save the day.

"I was glad to do it," says Drew, who is accustomed to coming to the rescue. "Whenever they call, I'm happy to donate. The blood bank phones me regularly to donate about every 2 months. Going to Congress was a pleasant experience for me."

In addition to being the first inductee in NIH's blood donor Hall of Fame in 1987 and the first to have made 100 donations at NIH, Drew is a highly decorated Army veteran. Over the course of a 36-year military career, he earned 16 medals and citations, including the Soldier's Medal for Valor and the Legion of Merit.

In 1945, after serving 2 years in the European Theater of Operations, he was traveling in an Army bus in Massachusetts when the vehicle crashed into a tree and burst into flames. After escaping from the overturned vehicle, Drew ran back to extricate another soldier trapped in the flaming wreckage. He carried his fellow passenger to safety, suffering burns on his hands and face. He was later cited for heroism.

Now age 75, Drew's latest acts of heroism may be much lower key, although equally important. Last month he was called downtown to meet Surgeon General Satcher and a few other volunteer

spokespeople to record several 30-second public service announcements on blood donation that will be distributed nationwide to blood centers, hospital blood banks and 600 television stations.

"I believe in the importance of community service, and nothing is as



On hand for "Fight for Life," an annual congressional blood drive challenge on Capitol Hill are (from l) Rep. Carolyn McCarthy (D-N.Y.), Drew and Rep. Fred Upton (R-Mich.). Held each January, which is National Volunteer Blood Donor Month, the contest between Republicans and Democrats gathered 300 donors from among congressional members and their staffs.

fulfilling as saving lives by donating blood," Drew says in one PSA.

"Blood donors like Howard are lifesavers," Satcher responds, inviting viewers to join Howard "to see how good it feels to give the gift of life."

"This was the first time I'd met the Surgeon General," said Drew, who has become something of



Congressman Upton and Drew roll up their sleeves.

a local celebrity himself over the last 50 years on the blood-donation circuit.

Drew said recording the PSAs was easy and fun and that he admired the work Satcher is doing, especially in trying to get the message out about the importance of volunteering to donate blood. No doubt the Surgeon General would express similar sentiments about Drew. **R**

Shown here in 1967 with empty bottles representing the more than 91 quarts of blood they had donated collectively are Howard Drew (l) and fellow champion NIH donors G. Richard Clague, Dr. Norman A. Hilmar and Forest Gray. At the time, Drew had given seven or more gallons; he now accounts for more than three times the amount shown below, by himself.



Take Your Child to Work Day, Apr. 27

NIH is sponsoring an educational opportunity for children during Take Your Child to Work Day on Thursday, Apr. 27. The purpose is to introduce children to the vital public services their parents provide and to encourage children to consider careers in medical research and the many supporting career fields. With approval of supervisors, employees may bring their children, ages 8 to 15, to participate in events from 9 a.m. to 4 p.m. The day will include hands-on labs, workshops and demonstrations on fire prevention and public safety. Check the web site at <http://www.cc.nih.gov/ccc/work/2000.html> for a list of events.

Due to the popularity of the program and space limitations, preregistration is required for some activities. Information on registration will be available at the web site. Parents are expected to accompany their children to all activities. Reasonable accommodation should be requested by contacting Gary Morin, 496-4628. For more information, call Brenda Robertson at 443-0913 or Joyce Starks at 402-6068.

Wednesday Afternoon Lectures

The Wednesday Afternoon Lecture series—held on its namesake day at 3 p.m. in Masur Auditorium, Bldg. 10—features Dr. Steven R. Cummings, who will give the Robert S. Gordon, Jr., Lecture in Epidemiology on Apr. 12. Cummings is professor of medicine and epidemiology and biostatistics, assistant dean for clinical research, School of Medicine, and director, UCSF Coordinating Center, University of California, San Francisco. His topic is “New Technology and a Two-Edged Sword: How Bone Densitometry Has Revolutionized and Impeded the Understanding and Prevention of Osteoporotic Fractures.”

On Apr. 19, Dr. Caroline H. Damsky, professor and vice chair, department of stomatology, School of Dentistry, professor, department of anatomy, School of Medicine, University of California, San Francisco, will discuss “A Fibronectin-FAK Signaling Axis: How Special Is It?”

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

Day of Prayer Set, May 4

A National Day of Prayer will be observed Thursday, May 4 by the Noontime Christian Fellowship, which will hold a prayer vigil on the lawn in front of Bldg. 1. Everyone desiring to pray for the nation and its leaders is encouraged to meet around the flagpole from 11:45 a.m. to 1 p.m. Guest speaker will be Minister Kevin Williams of Love & Faith World Outreach Church, Fort Washington, Md. ■

Program Analyst Nola Whitfield Retires

Nola Whitfield, a program analyst with NIDDK's Office of Scientific Program and Policy Analysis, has retired after 27 years at NIH.

She completed an M.Ed. in counseling psychology at the University of Maryland in 1974. She then began her career at NIH as a special assistant to the director of extramural affairs with the National Cancer Institute. A year later, she became assistant executive secretary for review of program project grant applications, serving as liaison between grant applicants, grantees and program directors; she also recruited reviewers and scheduled site visits to facilitate grants review.

At the same time, Whitfield played an instrumental role in developing NCI's Comprehensive Minority Biomedical Program and became its first coordinator. It was CMBP's role to generate interest in NCI research among minority investigators, an effort that often featured site visits. “Nola was unflappable, always calm and very pleasant,” says Dr. Paul Okano, a colleague from NCI's national cancer program minority advisory commission, who was also a member of the site visit team. She was the one who “was the real backbone of everything, and the corporate memory for a long time.”



Nola Whitfield

During her tenure with NCI, she twice received awards for the sustained high quality of her work. In 1985, she received an EEO Special Achievement Award, and in 1991, an NIH Merit Award for her “originality and creativity in developing the supplemental research awards concept” to support underrepresented minority researchers.

Moving to NIDDK, Whitfield joined what is now the Office of Scientific Program and Policy Analysis. She took primary responsibility for coordinating production of the institute's annual program plan with the operating programs of NIDDK. This compendium of research advances and proposed initiatives was presented annually to the NIDDK Advisory Council and distributed widely to the NIDDK research community. In addition, she served on the NIDDK minority affairs committee and coordinated a wide range of NIDDK minority health reports. “Nola is one of those dedicated individuals whose contributions are part of the strong fabric of the NIH,” says Carol Feld, NIDDK's associate director for scientific program and policy analysis.

On Whitfield's retirement, NIDDK director Dr. Allen Spiegel presented her with plaques commemorating both her NIH career and her efforts to develop the institute's programs to improve minority health and the participation of minorities in research.—Jane DeMouy ■

Substitution In FAES Chamber Series

The Apr. 9 performer in the FAES Chamber Music Series will not be Richard Goode, as had been advertised. Substituting will be Bradley Brookshire, harpsichord. The concert will still be in Masur Auditorium, Bldg. 10 at 4 p.m.

W:T AND WISDOM, CONTINUED FROM PAGE 1

care professionals in addressing the last phase of life.

Pre-play Reception Highlights Last Days

"The healthcare system in our country is primarily directed at treatment and cure," said Dr. Patricia A. Grady, director of NINR, at the reception prior to the play. "Technological advances that extend our lives are, however, also extending the time leading to death—a time when the quality of life remaining is not always what many patients want or expect." She also mentioned that this issue was brought to the forefront in the late 1990's by two major studies conducted by the Robert Wood Johnson Foundation and the Institute of Medicine of the National Academy of Sciences. These studies documented that pain was undertreated in dying patients, and that there were discrepancies between the patient's wishes and actual treatment received. The studies called for more research directed at palliative care—care that keeps the patient as comfortable as possible. In response to the two reports, NIH launched a program to stimulate research on end of life issues, with NINR serving as coordinator.

Other reception speakers included Dr. John Eisenberg, director of the Agency for Healthcare Research and Quality; Dr. Neil MacDonald, director of the Cancer Bioethics Program of the Clinical Research Institute of Montreal; Dr. Joanne Lynn, director of Americans for Better Care of the Dying; and David English, president of Hospice and Palliative Care of Metropolitan Washington.

The Play *W;t*

The spelling of *W;t* is not a typo. It has meaning within the context of the play. As the teacher points out to her young student in critiquing her paper on John Donne, "And death shall be no more, comma, Death thou shalt die." Nothing but a breath—a comma—separates life from life everlasting." The student, who had used a semicolon instead of a comma, grew up to be the central focus of the play—Dr. Vivian Bearing, a professor of 17th century poetry, specializing in Donne's Holy Sonnets. Bearing is diagnosed with stage IV ovarian cancer and, as she puts it, "There is no stage five." She enrolls in a clinical research trial, and the care by the healthcare team—not ideal by anyone's standards—includes ineffective pain control and failure to follow the patient's advance directive. Emphasizing the importance of knowledge and compassion, the play also effectively reflects public concerns about end-of-life care in a witty and powerful way. At the end of the performance, *W;t* received a standing

ovation that was immediate and long-lasting.

Post-play Q's and A's

After the play, most of the audience remained to participate in the forum "Beyond *W;t* — What Are the Questions? What Are the Answers?" Expert panelists included Dr. Betty Ferrell, a nursing research scientist from City of Hope National Medical Center; MacDonald; Lynn; Judith Light, lead actor; and the entire cast of *W;t*.

During the discussion, one of the panelists commented that the play was a superb teaching tool for medical students and can have a far-reaching impact beyond medical textbooks and journal articles. Actor Light indicated that as they performed, she and the cast could sense a rapport with the evening's research and healthcare-oriented audience, and she expressed admiration for their work.

How the Event Evolved

Except for the poet John Donne, few others have made a point of contemplating death until absolutely necessary. This denial helps to live life without the constant shadow of the inevitable, but denial also can help perpetuate less than desirable healthcare practices. Therefore, increasing awareness and creating scientifically based change become key. Some members of NINR saw *W;t* when it first opened in New York and recognized the play's unique ability to showcase many issues confronted by dying patients as they encounter the healthcare system.

When *W;t* was scheduled for the Kennedy Center's 2000 season, NINR initiated a collaboration with the center's department of education, which produces "Spotlight on Theater" discussions of selected plays. NINR then took steps to help a multidisciplinary coalition plan the educational event.

Members of the Coalition for End-of-Life Research and Care include NINR, National Cancer Institute, NIH's Office of Science Education, the Agency for Healthcare Research and Quality, Americans for Better Care of the Dying, Hospice and Palliative Care of Metropolitan Washington and Friends of the NINR. ■



Judith Light as Prof. Vivian Bearing, who has ovarian cancer, in the play *W;t*. (Photo by Joan Marcus)

Light answers a question from the Kennedy Center audience as Lisa Tharps, who plays the nurse Susie Monahan, looks on.





HRDD Training Tips

The Human Resource Development Division, OHRM, will offer the courses below. Hands-on, self-study, personal computer training courses are available through the HRDD's User Resource Center at no cost to NIH employees. For details, visit HRDD online at <http://trainingcenter.od.nih.gov/> or call 496-6211.

<i>Administrative Skills</i>	
Medical Terminology II	4/25
<i>Administrative Systems</i>	
IMPAC II - Quick View	4/24
<i>Communication Skills</i>	
Speed Reading	4/12
Scientific and Technical Briefing	4/27
Speaking on the Job Part I: Improving Voice Quality	5/1
Scientific and Technical Editing	5/2
<i>Computer Applications and Concepts</i>	
Intermediate MS Access 97 *Office 97*	4/12
Introduction to Web Page Design - HTML	4/14
Intermediate MS Word 97 *Office 97*	4/24
Introduction to Windows	4/26
Introduction to MS Excel 98 *Office 98*	4/27
<i>Career Transition</i>	
NIH Retirement Seminar - CSRS	4/17
<i>Financial & Procurement Management</i>	
Consolidated Purchasing Through Contracts	4/12
Buying from Businesses on the Open Market	4/13
Delegated Acquisition Training Program	4/20
<i>Management, Supervision & Professional Development</i>	
Managing Change: A Leadership Challenge	4/17
How to Delegate Effectively	4/24
How to Conduct a Performance Review	4/25
How to Manage Conflict: Solving Problems at Work	4/25

Healthy Married Men and Women Needed

The Pediatrics and Developmental Neuropsychiatry Branch, NIMH, seeks men ages 56-73 and women ages 51-59, to participate in an fMRI study on the visual processing of faces. Participants must be right-handed and currently married. Volunteers should have no history of psychiatric disorders, and should not be taking prescription medications, with the exception of hormone replacement therapy (estrogen and/or progesterone), thyroid medication, and/or medications for high blood pressure (diuretics or ACE inhibitors). Volunteers must have normal vision or wear contacts. Participation requires a 2-hour screening interview, a followup visit, and a 3-hour visit for fMRI scan. Participants will be paid. For more information about this study, call Lisa Kalik or Neil Santiago at 496-8381. ■

Celebrate Earth Day, Clean Your Files

NIH will mark Earth Day (Apr. 22) by hosting a Clean Your Files Week, Apr. 17-21. Use the week to recycle as much office white paper as you can, and to get rid of clutter. ■

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>.

Cost-Benefit Analysis	4/10
The NIH Contractor Performance System Update	4/10
Hands-On Web Animation	4/10, 13
Advanced Query and Reporting Workshop	4/11
WIG - World Wide Web Interest Group	4/11
SAS Fundamentals II	4/11-12
Introduction to Visual Basic	4/11-14
Data Warehouse <i>Analyze</i> : Human Resources	4/12
PC Viruses	4/13
Producing Tables with SAS	4/13-14
Functional MRI Data Analysis in MEDx	4/14
Introduction to Information Systems Security	4/17
Getting Started with GCG	4/17
Oracle PL/SQL for Application Developers	4/17-18
Good Web Page Practices	4/18
NIH Data Warehouse Budget Tracking	4/18
Advanced SAS Tabulate Features	4/18-19
NT Workstation Troubleshooting	4/19
Preparing Scientific Images for Publication and Display	4/19
Creating Presentations with PowerPoint 2000	4/20
Data Warehouse <i>Analyze</i> : Budget & Finance	4/20
Data Warehouse <i>Query</i> : Property Management	4/20

Males Needed

The Behavioral Endocrinology Branch, NIMH, is seeking male volunteers ages 18-45 to participate in a 5-month study of the effects of reproductive hormones on brain and behavior.

Volunteers must be free of medical illnesses and not taking any medication on a regular basis.

They will complete daily rating forms and be asked to participate in one of several protocols. Payment will be in accordance with the duration of each visit and the type of protocol. For more information, call Linda Simpson-St. Clair, 496-9576.

Be an NCI Cancer Prevention Fellow

The Cancer Prevention Fellowship Program (CPFP) trains physicians and postdoctoral scientists in the field of cancer prevention and control.

CPFP includes:

- Master of Public Health degree
- NCI Summer Curriculum in Cancer Prevention
- Mentored research at the NCI
- Brief field assignments at other institutions

For more information:

Cancer Prevention Fellowship Program
National Cancer Institute
Executive Plaza South, Suite T-41
6130 Executive Blvd MSC 7105
Bethesda MD 20892-7105
☎ (301) 496-8640
Fax (301) 402-4863
E-mail br24v@nih.gov

Visit our Web site
<http://dcp.nci.nih.gov/pob>



THE NATIONAL CANCER INSTITUTE IS AN EQUAL OPPORTUNITY EMPLOYER.

NIH Commits to Plain-spokenness

By Susan Persons

As Apr. 15 nears, it is easy to imagine a scene that Norman Rockwell might well have painted. The setting is the American kitchen, table covered with boxes of receipts and various papers scattered about, the clock on the wall nearing midnight, and a frustrated individual scratching his or her head, struggling to understand a tax form. Many skeptics would say that this image is real—and immutable.

Nonetheless, whether it is tax forms, instructions regarding social security benefits, or health messages from NIH, the federal government is initiating a plan, the Plain Language Initiative, to make all communication with the public “more responsive, accessible and understandable.” And NIH is determined to make this effort a success. “It is important that the mission of the NIH be stated in ‘plain language’ so it is understood by the American people who stand to benefit by our research endeavors,” said Dr. Ruth Kirschstein, acting NIH director.

What is the Plain Language Initiative?

The Plain Language Initiative requires the use of plain language in all new documents written for the public that explain how to obtain a benefit or service or how to comply with a requirement. By Jan. 1, 2002, everything the federal government publishes must conform to this requirement. Plain language is a style that requires the writer to focus on what the reader needs to know, rather than what the writer wants to say. (Correction: It is a style of writing that requires a focus on what you need to know, not what I want to say. Yes—the use of personal pronouns is not only allowed but also preferred!)

For most of us this initiative will require that we

“unlearn” many writing techniques that have become habitual. We will need to form new habits such as: writing in the active instead of the passive voice (for example, “Kirschstein decided that...” rather than, “It was decided that...”); using common, everyday words instead of words we need a thesaurus to find; shortening our sentences; making more use of lists, tables, graphics and “white space”; and using the “question and answer” format to organize material around the interest of the reader.

These techniques are but a sampling of a way of writing that simply makes sense. To find out more about how to write in plain language, visit the National Partnership for Reinventing Government Web site at www.plainlanguage.gov.

How will NIH implement the initiative?

Under the leadership of Karen O’Steen, director of the NIH executive secretariat, NIH has taken several steps to implement this Presidential directive. She has briefed institutes’ and centers’ correspondence contacts and has sent a memo to IC directors and OD staff. She has introduced a plain language section to the exec sec web site at <http://www1.od.nih.gov/execsec/plainlanguage.htm>. In addition, O’Steen has organized a plain language coordinating committee composed of representatives from each IC. The PLCC has established three subcommittees: a media subcommittee that will address how NIH will inform staff and promote the initiative; a training subcommittee that will focus on how NIH will provide employees with the tools they need to write in plain language; and an evaluation and awards subcommittee that will determine how this initiative will be evaluated and successful efforts rewarded. The executive secretariat will soon include a list of IC representatives on its web site should you wish to contact yours with questions.

What resources are available?

The training subcommittee is developing a resource list of recommended sources and means of training, including videotape sessions, web-based training, and specialized group training. Also, training opportunities are already available through the NIH Training Center. At its web site, <http://trainingcenter.od.nih.gov/>, under Communication Skills, you will find listed a course on Plain Language in Government Writing and a course on Scientific and Technical Writing. In addition, the executive secretariat is available to give you assistance with an individual document, refer you to resources, provide specialized training, and more. Contact them at 496-1461.

If you have succeeded in changing bureaucratese into plain language and wish to share the “before” and “after” documents, forward them to O’Steen in Bldg. 1, Rm. B1-44. ■



Officials of Lakota Technologies, Inc. of Eagle Butte, S.D., recently met with NLM director Dr. Donald Lindberg and Sheldon Kotzin, chief of the library’s Bibliographic Services Division, to discuss progress made on their contract with NLM to perform data entry tasks associated with the creation of OLDMEDLINE.

OLDMEDLINE is a database containing citations to articles in biomedical journals published between 1960 and 1965. Lakota Technologies is a commercial operation of the Cheyenne River Sioux Tribe, whose reservation is located on 2.8 million acres (an area the size of Connecticut) in north central South Dakota. Shown above are (from l) Leroy LaPlant, Jr., administrative officer, Cheyenne River Sioux Tribe; Lindberg; J.D. Williams, executive officer, Lakota Technologies, Inc.; and Gregg J. Bourland, chairman, Cheyenne River Sioux Tribe.