Is There Any Good Way To Give Bad News?

By Rich McManus

While everyone knows that into each life some rain must fall, opinion varies on the circumstances that call for deployment of an umbrella. A panel of NIH caregivers recently discussed this and related issues at a lecture entitled, "The Delivery of Bad News to Patients."

Asked how they have learned to break tough news to patients—not an uncommon occurrence at the Clinical Center, which specializes in the most difficult medical problems—six experienced patient care workers offered a wealth of opinion.

"It's important to be very honest with patients and tell them exactly what's up," said Dr. Steven Rosenberg, chief of NCI's Surgery Branch. "Trust lies at the very heart of the interaction between patient and physician."

An innovator in the use of immunotherapy—enhancing the body's own warrior cells chemically to combat cancer—Rosenberg stressed the importance of leaving bad news with a measure of hope.

"Most often, our treatments don't work," he admitted. "But it is important always to leave the patient with some hope. Patients say the worst thing is to have no hope at all. We leave them with some hope, patients say, 'I'm a little better.'"

By Anne A. Oplinger

Slender trees with graceful, fan-shaped leaves, Ginkgo biloba shade many urban sidewalks. They are favored for city landscaping because of their ability to thrive in poor soil, on little water and while surrounded by smoke and car exhaust. One well-known drawback of these hardy trees is the distinctive, unpleasant odor emitted by female ginkgos.

What many modern city dwellers do not know, however, is the important role that ginkgo leaf extracts have played in traditional Chinese medicine for the past 5,000 years. Ancient Chinese herbalists used ginkgo leaf extracts to treat heart and lung disorders, and the extracts are used in China today to treat hypertension. In France and Germany, drugs made from ginkgo leaf extracts are used to prevent tissue death that can occur if blood vessels constrict and deprive the tissue of oxygen.

The active ingredient in some of the drugs derived from ginkgo leaves is ginkgolides, cup-shaped molecules formed by six connected pentagonal rings. One of the ginkgolides, ginkgolide B, has been found to exert strong inhibition of platelet activating factor (PAF), a substance found in animals. Although its role is not completely understood, it is known that PAF is present when cells are inflamed—for example, in asthma attacks, transplanted tissue rejection, toxic shock and anaphylactic shock (a life-threatening allergic reaction in
Ginkgo
(Continued from Page 1)

which the lung passageways constrict).

Because ginkgolide B inhibits the action of PAF, it can ameliorate the lung constriction characteristic of anaphylactic shock. It has also been shown to promote recovery in animals after a stroke, to prolong the survival of transplanted hearts in rats and to be effective in treating people with asthma. Moreover, ginkgolide B has no known toxicity.

Full-scale studies of the actions of ginkgolide B under various conditions have been hampered by the unavailability of large quantities of purified ginkgolide B derived from tree leaves. The substance also proved extremely difficult to synthesize "from scratch." After much effort, however, Dr. Elias J. Corey, an NIGMS grantee at Harvard University, has made ginkgolide B in the laboratory. Twenty-four steps, some of which must be performed at extremes of temperature, are required to synthesize the molecule.

Corey and his colleagues will now attempt to streamline the synthesis to make it more practical for the large-scale production of ginkgolide B. However, it is unlikely that ginkgolide B will ever be used as a drug since, because of its large size, it is not absorbed well when given orally. Nevertheless, the chemical steps devised by Corey and his team to synthesize this exceedingly complex molecule will help scientists synthesize smaller, related molecules that will be absorbed more readily and that therefore may have therapeutic value.

Modern chemistry will no doubt be used to refine the properties of ginkgo tree extracts, but ginkgos themselves are among the most ancient and primitive of trees. Ironically, the tree that provided the material for developing this drug is extinct in the wild. It was preserved by Buddhist monks in Japan and China who considered ginkgos sacred and planted them outside their temples. If valuable drugs can be made from the ginkgo extracts, many people will consider it fortunate that this simple tree was saved and cultivated.

Discount Tickets to Ford's Theatre

R&W has discount tickets to American Juke Box at Ford's Theatre on Sunday, Apr. 23 at 3 p.m. Cost for the tickets, which must be purchased by Apr. 6, is $23.50 (regular price $26.00). For more information, contact the R&W Activities Desk, 496-4600.

Orioles Tickets at R&W

R&W is an authorized ticket agent for all Orioles games played at Memorial Stadium. For more information, contact the R&W Activities Desk, 496-4600.

‘Design of Life’ Focus of Exhibit

Images of molecular structure are the focus of the exhibit “Design of Life,” sponsored by the DeWitt Stetten, Jr. Museum of Medical Research in cooperation with the NIH Clinical Center Galleries. Located in the lobby of the Lipsett Amphitheater, Bldg. 10, and running through May 31, the exhibit examines the marriage of science and art in depicting molecular structures of the human body. It features the molecular art of scientific illustrator Irving Geis.

A set of historical photographs traces the evolution of medical art from the Renaissance drawings of Leonardo da Vinci and Andreas Vesalius through Paul Ehrlich’s early 20th century speculative sketch of how antibodies might function.

A model of staphylococcal nuclease and two models showing the variable and constant parts of an antigen-binding fragment of a mouse antibody reflect the three-dimensional model-building approach used during the 1960’s and 1970’s by investigators studying protein structures. Built at NIH by Dr. David R. Davies of NIDDK and colleagues, these models revealed the complex conformations of proteins.

During the early 1960’s, scientific illustrator Irving Geis began to collaborate with various investigators to produce paintings that illuminated the structure and activity of protein molecules. Using color and light, Geis created striking visualizations of proteins, DNA, viruses and other molecular structures. Thirty-two of his drawings and paintings are included in the exhibit.

A new art form, “non-neon light,” was used by Richard Feldmann of DCRT to visualize the triose-phosphate-isomerase (TIM) molecule, whose shape is one of the most common among known protein structures. Brightly colored plastic traces the major structures of the TIM molecule and permits conceptualization in three dimensions.

Computer graphics are now widely employed to visualize molecular structure. The exhibit concludes with a videotape, “Generating a Molecule,” originally prepared by Dr. Byungkook Lee of DCRT to show his colleagues how to construct computer-generated images.

On Apr. 25 at 4 p.m. in Lipsett Amphitheater, Dr. Roald Hoffmann, a Nobel laureate in the department of chemistry, Cornell University, will present a talk, “Molecular Beauty,” in conjunction with the exhibit. The public is invited and will have an opportunity to talk with the creators of the exhibit objects at a reception afterwards. For additional information about the exhibit, contact Dr. Victoria A. Harden, curator of the museum, 496-6610.

The NIH Record

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NCI Physicians Win Cancer Research Awards

NCI scientists Charles E. Myers, Steven A. Rosenberg and Lance A. Liotta recently received $50,000 each from the Milken Family Medical Foundation of California for their contributions to cancer research. This annual award program gives public recognition and financial reward to distinguished researchers in clinical and basic science who have made, or who are on their way to making, significant contributions to the diagnosis and treatment of cancer.

Myers, chief of the Medicine Branch, Division of Cancer Treatment, was recognized for his research on intra-abdominal delivery of anticancer drugs, management of adriamycin cardiac toxicity, and development of new drugs to overcome tumor resistance to anticancer drugs.

Rosenberg, chief of the Surgery Branch, Dr. Steven A. Rosenberg

Liotta, chief of the Laboratory of Pathology, Division of Cancer Biology, received the award for leading the research that led to the discovery and isolation of four gene products that may play a role in cancer metastasis (the spread of cancer). These gene products have been proven useful in cancer diagnosis and are the targets of experimental treatments for metastasis.

The Milken Foundation also presented four other cash awards to other investigators in North America.

DIV Chapter Honored

The NIH chapter of Blacks in Government received the distinguished service award from the National Blacks in Government organization for its efforts to eliminate institutional racism. The award, given in the form of a plaque, was presented to the NIH chapter president, Sylvia Stewart.

All employees are invited to view the plaque, currently on display in the Bldg. 31-A wing lobby. It is planned that the plaque will be rotated among the following NIH buildings during the next 6 months: Bldg. 10, May; Bldg. 1, June; Bldg. 38A, July; Executive Plaza, August; Federal, September; Westwood, October.

Volunteer Interpreters Needed

The Clinical Center volunteer program needs foreign language interpreters to be on call especially during evenings and weekends. Interested persons should contact Linda Quick, 496-1807.

Program and 21 special interest programs.

Volunteers, who represent a seemingly endless resource of interest and skills, help patients adjust more easily to a research hospital environment. By the care and sensitivity they show, volunteers help staff relieve patients' apprehension and demonstrate that people do genuinely understand patients' emotional needs and the courage it takes to participate in research.

Volunteers work as language interpreters, patient advocates, unit clerk assistants, hospital guides, escorts, temporary companions, recreation aides, pharmacy aides and laboratory assistants. Several can be found in outpatient clinics, at information desks, and preparing recruitment or informational literature for nursing services, clinical studies, patient education and new employees.

Guided by the theme "Celebrate the Art of Volunteering," the CC will pause next week to reflect on these dedicated people and the vital role they play.
Nobel. The 30-foot-long exhibit, which is on loan to NIH, traces Nobel's scientific accomplishments and the development and history of the Nobel Prizes.

In his remarks to the audience, which included three of the four former and present intramural NIH Nobel laureates, Wyngaarden observed that NIH-supported researchers have won 15 percent of all the Nobel Prizes ever awarded. "When over 90 plaques are in place," he said, "this terrace will stand as a testimony to that accomplishment and provide the recognition that this prize truly deserves."

Wyngaarden also expressed hope that the Nobel Terrace would inspire future generations of young people to pursue academic careers in science. Recently, the number of students pursuing careers in scientific research has declined. Comparing the Nobel Terrace to professional football's Hall of Fame in Canton, Ohio, which honors that sport's heroes and inspires new generations of athletes to excel, Wyngaarden said that in turn "this Nobel Terrace honors our heroes. It is our hall of fame. We need to inspire youth with the adventure and excitement of scientific research. And that's what this exhibit is attempting to do."

Following the remarks and ribbon-cutting ceremony, guests were treated to a genuine smorgasboard buffet fit for a Swedish king, or a count as was the case.

The Nobel Terrace is the latest addition to a series of improvements in the NIH Visitor Information Center. These improvements include interactive educational exhibits, which are being installed on the main floor of the VIC. According to Thomas Flavin, NIH special projects officer, "NIH hopes to siphon off some of the 23 million visitors who visit the Washington, D.C., area each year to come to NIH. We also hope that our exhibits will prove interesting and educational to the NIH community and their families."

For further information about the Nobel Terrace or any other exhibits in the VIC, call 496-1776.

Photos: Bill and Ernie Branson, DRs

Cutting the ribbon to open the NIH Nobel Terrace are (from l) Wyngaarden, Wachtmeister and Molitius. Pharmacia, the Swedish pharmaceutical company, sponsored the ceremony and luncheon buffet.
Harvard Professor Asks: 

Do We Need Lawmen in the Laboratory?

By Rich McManus

With recent headlines reporting new cases of fraud in scientific research, it would be easy for the layman to conclude that the scientific enterprise is faltering.

But that is not what is going on at all according to Dr. Bernard Davis, professor emeritus at Harvard Medical School and a visiting Fogarty scholar at NIDDK.

Addressing the topic, "What most threatens the integrity of science?" Davis defined integrity for a Clinical Center Grand Rounds crowd at Lipsett Amphitheater:

"The true integrity of science doesn't mean zero fraud, it means dedication to promoting the maximum output of valuable knowledge. Since we scientists build our whole enterprise on trust, we have stronger reasons than legislators to refrain from even the appearance of fraud, but we also recognize the importance of preserving an atmosphere that encourages creative science.

"Fraud is a real problem," he added, "and many of our institutions have not responded adequately. Congress is justified in pressing them to do better. But if policing efforts go too far they will do more harm than good."

Davis also emphasized the importance of distinguishing fraud from error.

"Error, he said, is inevitable in science and the scientific community learned long ago how to deal with it. In many ways the scientific enterprise is better off for the errors it has committed. As a result, scientists feel empowered to question the literature and make corrections when necessary."

In the end, Davis said, the problem of fraud is one that can be built upon, not fixed. "It is the nature of science to change with the passing of time, while errors or conclusions have a brief life: nature is the ultimate authority."

Davis appears to favor a vigorous world where truth and error are allowed to collide, unhampered by layers of bureaucratic monitoring. What he fears is that Congress, which funds much of American science today, may be getting the impression that laboratories need policing. Davis sees a rigid science emerging from such an environment, and one that will attract fewer and fewer agile minds.

It is absolutely proper, he said, for universities, and for NIH, to act vigorously on charges of misconduct and to punish real fraud severely. It is another matter, however, for the government to get into policing quality of research, training, and publication practices. These are responsibilities of academic institutions and the scientific community, and the government already has a mechanism for influencing standards through its grant review committees.

Davis used two colorful comparisons to describe the atmosphere surrounding the conduct of science today.

"Like fraud in science, child abuse is a major issue in current society, he related. But we surely will not send inspectors into every house with children to see if abuses are being committed there and we should be no more willing to send inspectors into laboratories.

Another comparison involves speed limits.

"When I was young," Davis recalled, "anything over 35 miles an hour was speeding. Now, at 55 to 65 mph, the death rate on the highways is much higher, but it is seen as an acceptable price for the benefits of rapid transportation."

In what he called a heretical view, Davis suggested that the enormous rate of progress in highly competitive fields of science today may only require us to tolerate, similarly, a rate of misconduct higher than that in the past—as long as it is still a very small fraction of the total research we do. "We surely do not wish to slow everyone, and waste substantial resources, in pursuit of unattainable purity."

Ending his talk, Davis noted that in reviewing the autobiography of Francis Crick (a founder of the field of molecular genetics) he characterized Crick's nature as "clint.

"A playful spirit is essential to science," he said. As a way to preserve integrity, boldness and creativity in science, Davis recommends avoiding anything that would thwart or intimidate the spirit that.

NIH'ers May Join Parade

Be a part of the Bethesda-Cherry Chase Parade. On Sunday, May 7, Wisconsin Ave. will be transformed into Main Street USA with an old-fashioned hometown parade featuring marching bands, antique cars, balloons, clowns, majorettes, Shriners, mini-cars and mounted police. Employees of NIH are invited to get involved. If you would like to be in the parade or organize a group to participate (band, antique cars, float, costumed characters, etc.), call Kelly Goka or Karen Muggeo in the R&W Office, 496-6061.  

Unpaid Interns Available

Undergraduate interns with backgrounds in all medical fields are available for summer internships approximately 6-10 weeks long. Please contact Peter Abajian at the Armenian Assembly of America, 393-3434, for further details.

Apply Now for Grants Workshop

A workshop on extramural programs and grant support, designed to help postdoctoral fellows understand the research grant process, will be held in Lister Hill Auditorium, Bldg. 38A, on Friday, June 2, from 8:30 a.m. to 5 p.m.

The workshop, sponsored by the National Institute of General Medical Sciences, is intended for intramural postdoctoral fellows, staff fellows, clinical associates and research associates who will be leaving NIH during the next year. Others will be considered for participation if space allows.

The program will cover the types of federal and non-federal support available to new investigators, the NIH review process, the fine points of preparing a grant application and appropriate persons to contact with problems or questions.

Small group discussions for answering individual questions will be led by experienced staff people from several institutes.

Application forms are available from intramural laboratory and branch chiefs. Applications must be returned by Apr. 28 and should be sent to Extramural Workshop, Rm. 905, Westwood Bldg.

For additional details, call Dr. Yvonne Maddox, 496-7001, or Dr. Loré Anne McNicol, 496-0534.

Demonstration and Classes on FOCUS

Two NIH computer specialists will hold a demonstration of FOCUS, a database management system on the NIH mainframe computer, Thursday, Apr. 13, from 9 to 10 a.m. in Bldg. 12A, Rm. B47. In addition, classes will be held Apr. 25 and 27 for anyone wishing to learn more about the system.

FOCUS has an easy-to-use query language that can be learned in a half-day class. It provides a quick and simple way to develop reports and files that can be useful to many employees including secretaries, grants management specialists, budget analysts and health scientist administrators. Extramural staff may be particularly interested in a FOCUS file of grants data that is updated nightly by DRG.

To attend the demonstration or one of the classes, call Lee Vickers, NIGMS, 496-7303; Sheldon Fishman, OD, 496-5011; or Carolyn McHale, NIAMS, 496-0799.

Washington Ballet Tickets

R&W has discount tickets to the Washington Ballet Spring Repertory Series on Saturday, May 13 at the Kennedy Center (Eisenhower Theatre). Tickets for the 7:30 p.m. performance are $27 (regular price $30); tickets for the 2 p.m. matinee are $22.50 (regular price $25). All tickets must be purchased at least 1 week in advance.
First Anniversary Marked

Teen Group for Cancer Patients Benefits All Parties

By Rich McManus

Though it is traditionally an awkward time for anyone passing through it, the teenage years can be especially difficult for teens with cancer.

For that reason, a group of three NIH employees has created its own extracurricular teen group for patients at NCI's Pediatric Branch and other area hospitals. The group, which has just completed its first year and is planning activities for 1989, seeks mainly to promote normal adolescent development.

"We recognized that these kids had problems besides cancer—family troubles, problems communicating with parents and peers, and adjustment problems at school," said Donna Wilson, a social worker on 13 West at the Clinical Center.

Wilson, along with recreational therapist Holly Cobb, agree that the impetus to start the group came from Charles Butler, who supervises the hospital's pediatric recreation program for the patient activities department.

"Charles got the idea when he took some kids from Camp Fantastic (a summer camp for children with cancer) on a weekend trip for teenagers in Pennsylvania," recalls Wilson.

"He saw what a wonderful group process went on.

The three NIH employees held their first meeting in November 1987 to discuss organizing a teen program here; 3 months later a group of teenage NIH patients held its inaugural meeting.

"We sent a letter to all cancer patients ages 13 to 17 at the hospitals that send kids to Camp Fantastic," said Wilson. The camp's executive director, Dave Smith, immediately joined Butler, Cobb and Wilson in the project.

In March 1988, the group—then about 15 strong—took its first trip together. Destination: Ocean City, Md.

"It was fun," remembers Cobb. "It gave the kids a chance to interact with others in the same situation (having cancer)."

A young female patient on the trip whose cancer treatment had left her bald said that, for the first time, she felt comfortable enough to remove her wig and be herself, said Cobb.

"The group provides inspiration and courage for younger members who see older ones who have survived and done well," she observed.

The group took its second trip—a whitewater canoeing excursion down the Shenandoah River—last June. That was followed up in September by a return to Ocean City made possible by the Make-A-Wish Foundation there, which also sponsored the first beach trip.

"Humor comes out on these trips," Wilson noted, "but there is a serious side, too. Three of the kids who had made the March trip were unable to be there in September. One died unexpectedly, one had a heart transplant and one relapsed."

"We gave them a safe environment to grieve about these three," said Cobb. "Out of that came a request from the kids to talk to their parents more openly about death and dying. Previously, they were reluctant to bring it up."

"It was very difficult for the parents, but they were relieved at the end to have done it," said Wilson.

Parents meet informally among themselves while their children attend teen group meetings. "It's real good for parents from other hospitals to meet and support each other," said Wilson.

At the end of their separate meetings teens and parents get together as a group to discuss issues.

This year's agenda includes a family picnic in May on the grounds of the Clinical Center and another raft trip in June.

"It was such a success last year that we decided to do it again," said Cobb. "The kids just loved it. The Friends of the Clinical Center paid for the adventure last year."

On July 15, the group will travel to Memorial Stadium in Baltimore to watch the Orioles play baseball on "Special Love Night," named after Special Love Inc., the group responsible for Camp Fantastic.

The group would like to take a 1-day overnight mountain retreat in late September, but needs a place to stay. Anyone having mountain property within 3 hours of Washington is urged to call Wilson, 496-1605, or Cobb, 496-0147.

A priority for group members in 1989 is to hold more functions that their friends can attend.

"We're always recruiting new members," said Cobb. "There's no limit to the number we can accommodate."

Completion of the Children's Inn at NIH, a home-away-from-home for pediatric patients treated here, is expected to be a boon to the Holly Cobb (l), a therapeutic recreation specialist, and Donna Wilson, a social worker, have extended their duties to include a teen group for NCI Pediatric Branch patients and other young cancer patients from local hospitals.
rafting down whitewater in the Shenandoah River are members of a teen group organized by NIH employees for area cancer patients. On board are two of the group’s counselors, Dave Smith (second from left) and Donna Wilson (third from left). The group recently celebrated its first anniversary and is planning more trips for 1989.

Pregnant Vols Needed

For a study of pregnancy and the postpartum period, interested volunteers who are in their first pregnancy (between 16 and 18 weeks) can call Dr. Douglas S. Rabin, 654-2964, between 9 a.m. and 5 p.m. and leave name and telephone number. The call will be returned, and any questions answered at that time. Participants will be reimbursed.

New Branch Formed at NEI

The National Eye Institute has announced the formation of a new Ophthalmic Genetics and Clinical Services Branch within the institute’s intramural research program. The new branch will coordinate and focus basic and clinical research on genetic ocular diseases in a way that will expedite the translation of new research information to patient care.

Dr. Muriel I. Kaiser will serve as chief of the branch. She has been head of NEI’s section on ophthalmic genetics and pediatric ophtalmology in the Clinical Branch. As branch chief, Kaiser will also serve as the NEI representative to the Interinstitution Medical Genetics Program (IMG) that coordinates consultative services of genetic specialists from among the institutes and the training of IMG fellowship students.

The new branch will conduct laboratory and clinical research on gene expression and molecular interactions that affect the eye and visual system. Research findings will then be applied to the prevention, diagnosis and treatment of diseases such as corneal disorders, cataract, retinal diseases and abnormalities of the visual pathways. At present the major areas of research within the new branch are cataract and inherited retinal diseases, including gyrate atrophy and retinitis pigmentosa.

NIH Relay Set for May 17

The NIH Health’s Angels running club has scheduled the 12th running of the Institutes Challenge Relay for May 17. The Allen Lewis NIH Memorial Trophy will be inscribed with the winning teams from all three divisions: all male team, all female team, and mixed team (members must include at least two females).

As usual ribbons will be awarded to all runners. A post-race party is planned that afternoon at the FAES center.

The relay will be held at noon in front of Bldg. 1. The relay team is comprised of five runners, each of whom runs a half-mile loop around Bldg 1.

A $5 entry fee per team will help defray the cost of the race. Entry forms and specific instructions will be available at the R&W Activities Desk located in Bldg. 31, Rm. B1W30 beginning Monday, Apr. 17. Completed forms and payment in the form of a check to the R&W must be returned to the Activities Desk by Friday, May 12.

The relay is primarily intended to promote friendly and constructive competition among members of the NIH community. Participants of all levels of ability are very much welcomed to share in this annual spring event.
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emphasize the positive side of the picture, even if the news is bad.”

Members of the medical care team, which, in addition to the physician often includes a primary care nurse, a social worker and a chaplain, must “place correct emphasis early in the relationship on trust, openness and responsiveness to both the easy and difficult questions,” said Andrew Tartler, an NCI administrative officer who spent 5 years as a social worker for the institute’s Pediatric Branch.

“There are questions behind questions that must be discerned,” he said. “It’s important to repeat information that is hard to hear. Bad news is hard to take at first so it must be repeated.”

Nurse Maureen Sawchuk of the Cancer Nursing Service stressed the value of the nurse to the physician who must deliver bad news. “It is very difficult and very uncomfortable, but we need one another for support in the process,” she said.

Echoing the importance of a team approach was Dr. Frederick Ognibene of the Clinical Center’s critical care medicine department, where the most gravely ill CC patients are often found.

“Patients who come to us are generally very, very sick. Many times they are too sick to appreciate the impact of the news. We deal most often with families of acutely ill and dying patients.”

Ognibene said he and his colleagues strive to identify themselves to family members, to put them at ease in a threatening environment of high technology.

“We try to explain what the lifesaving machinery does and to emphasize personal contact,” he said. “But we rely very much on the home team of physicians and nurses. Their input helps relieve the unfamiliarity of the intensive care unit.”

Physician Trey Sunderland, who works with Alzheimer’s disease patients, thought that delivery of that frightening diagnosis would be the toughest news he would have to offer patients.

“Having to say that there is no more treatment that we can offer is really the worst news,” he said. “We try to give the information over and over again, in three different languages if necessary.”

What if family members ask that a patient be kept in the dark about his or her diagnosis, wondered Dr. Alison Witchman, a neurologist and bioethics expert who moderated the discussion.

“It is not possible to not reveal critical information,” stated Rosenberg. “We say right from the start our policy is to be perfectly honest and that we will not withhold information—that’s part of the contract from the beginning. A physician can’t give good care without honesty.”

He allowed that it is appropriate for physicians to withhold information that is not asked for, such as survival estimates.

“Some details are best left for another time or ignored if the patient doesn’t care to know them,” he said.

“It seems that many NIH patients are more inquisitive than patients at other hospitals,” observed Dr. James Balow, chief of the kidney disease section in NIDDK’s Metabolic Diseases Branch. Rather than remain in the dark, CC patients frequently can’t get enough news about their conditions.

“Some patients complain that I give them information overload,” said Balow. “Others say they trust me to give them only as much news as they can handle.”

Moderator Witchman asked panelists what constituted the worst part of bearing bad news, with some surprising results.

“Our unit has learned that bad news is really a two-way street,” said Sunderland. “A sense of failure on the part of the staff is hardest to deal with, not fear of how the patient will react.”

Encountering such denial on the part of a patient or family is an unpleasant outcome, said Tartler, who ranked an absence of team consensus about the patient’s prognosis as the second worst pitfall.

“It’s hard to give bad news to people you don’t know very well,” offered Ognibene.

“We are often the ultimate deliverers of bad news and consequently are seen as bad people. We really need the support of the home team (primary nurse and physician).”

“I’m surprised at how well patients sometimes do react,” said nurse Sawchuk. But she acknowledged that a particularly painful experience is witnessing the graceless manner with which some young physicians break unhappy news to patients.

“Physicians are the ones who most often have to give bad news,” she said, “but they are never taught in medical school how to do it.”

Rosenberg agreed that giving bad news “is possibly the most difficult thing a physician has to do. But it is not a team process at all, in my view. You don’t want any crowds on hand, just one or two people. Patients can then react freely and in a way natural to them.

“It’s hard to get experience in this field,” he noted. “It is often not taught very well in medical school. It’s an acquired skill.”

Rosenberg recounted that patients react differently to bleak news.

“Some patients try to cheer you up. Some patients get hysterical. Some patients get angry, sometimes at the doctor.”

His prescription for good results? “Don’t raise unrealistic expectations prior to the administration of care. Make sure the patient understands all possible realistic outcomes beforehand.”

Balow said that bad news becomes more palatable when all members of the health care team know what the physician has told the patient.

“Team conferences assure consensus on how news should be delivered,” he said. “There are going to be repercussions that need to be dealt with.”

The two physicians were emphatic about how not to give bad news.

“Don’t deliver significant news in a casual way,” Rosenberg warned. “It is very destructive.”

Said Balow, “The most threatening bearing a physician can have is to appear to be in a hurry. You’ve got to hear a patient through the whole process and let them know of the resources that are available to them.”

Witchman said that a quality of dialogue must characterize the physician-patient relationship, even at grave junctures: “Caregivers must be careful not to assume they know exactly how the patient will react to bad news. Assumptions are dangerous.”

Numbing the sting of even the worst news was an observation made by psychologist Sunderland of NIMH.

“The hope (among patients) that participation in research has helped the world in some way is very common at NIH, even among those with poor prognoses.”

The discussion was sponsored by the Educational Services Office, CC, as part of a series focusing on bioethical issues entitled, “Life-Threatening Illness: Living with Dying.” All earlier talks in the series are available on videotape.

Two more lectures in the series are coming up soon, “Bioethics in the Clinical Center,” will be held Apr. 13 from noon to 1 p.m. in Lipsett Amphitheater. “A Patient is More Than a Chart: Culture, Religion and Illness,” will be held from 8:30 a.m. to 5 p.m. May 4 in Wilson Hall, Bldg. 1. Call 496-1618 for more information about these talks.
Endoscopy to Control Bleeding Ulcers Proves Effective

By Jim Fordham

Techniques using fiberoptic endoscopy are effective in the treatment of bleeding peptic ulcers in managing high-risk patients, according to a recent NIH consensus development panel. The two most effective techniques are multipolar (or bipolar) electrocoagulation and the heater probe. Laser photoagulation and injection therapies may also be effective but deserve further evaluation according to the consensus statement issued by the panel.

"Peptic ulcer disease is a major health problem that affects more than 4 million Americans and costs the nation about $3.2 billion each year," said panel chairperson Dr. Donald O. Castell, chief of gastroenterology, Bowman Gray School of Medicine, Winston-Salem, N.C. According to Castell, about 85 percent of patients with acute upper gastrointestinal bleeding stop bleeding spontaneously. The remaining 15 percent have a life-threatening bleed and may require some form of therapeutic intervention.

More than 100,000 patients a year bleed from peptic ulcers. Despite advances in diagnostic and treatment, the mortality rate from bleeding ulcers has averaged between 6 and 10 percent during the past 30 years.

Dr. J. Loren Pitcher of the University of New Mexico Medical Center said remarkable advances have been made in diagnostic and therapeutic endoscopy since the last consensus development conference on gastrointestinal endoscopy was held at NIH in 1980. He said that these advances have "enhanced our knowledge of the pathology of bleeding ulcers and have allowed the identification and selection of patients who have a very high risk of ongoing bleeding or rebleeding and a need for more urgent and definitive therapy." He said endoscopic therapy "is safe and effective and should soon be more widely applied to clinical patient care."

"The technique that has shown the most promise is the heater probe," said Dr. Frank Hamilton, NIDDK gastroenterology program director and chairman of the conference planning committee. "The heater probe is passed through the endoscope and placed against the bleeding ulcer. Heat is applied and the bleeding stops. The bipolar or multipolar electrocoagulator works much the same way. Instead of heat, a small amount of electrical current is delivered through the probe applied directly to the bleeding blood vessel."

Other treatments the panel found effective were the Nd-YAG laser and injection therapy (sclerotherapy), in which agents such as sodium chloride, epinephrine and ethanol are injected at the site of the ulcer. Both techniques require further study. The panel found the laser to be comparatively expensive and more difficult to learn than other endoscopic methods.

The consensus panel agreed that a major predictor of significant persistent or recurrent bleeding was the amount of blood loss before the patient was evaluated. The panel also stated that disorders of blood coagulation and the onset of bleeding in a patient after hospitalization were predictive of further severe bleeding. The first and most important predictor of persistent or recurrent bleeding was profuse bleeding at the time of endoscopy.

"In the evaluation of upper gastrointestinal bleeding, endoscopy has assumed an important role because of its diagnostic accuracy," said Dr. James H. Johnston of the University of Mississippi School of Medicine. "In 95 percent of cases, the bleeding site can be reliably determined by finding a stigma of hemorrhage marking the lesion. For peptic ulcers, these stigmata may include active bleeding, an adherent clot, a protuberant mound (popularly called a 'visible vessel') or a flat spot in the ulcer base."

The panel stated that some "pigmented protuberances" (red, blue or white mounds in the ulcers) indicate a high risk of rebleeding, even when not associated with active bleeding during endoscopy. Implications of "visible vessels" and the anatomic locations of ulcer craters were not considered clearly prognostic of severe or persistent bleeding. Patients at low risk for rebleeding were those whose ulcers have a clean ulcer base or a flat, pigmented spot.

Complications of therapeutic endoscopy are common in some situations, particularly when patients are hemodynamically unstable with low blood pressure from excessive bleeding, or when there are other illnesses such as diabetes or kidney failure. Other patient characteristics that are associated with a high risk of complications are the "depth and location" of the ulcer and "excessive depth of penetration of energy or injectate" during therapy. There was agreement that therapeutic endoscopy should be performed only by an endoscopist who is experienced and qualified in the specific technique. In such hands, the rate of complications of therapeutic endoscopy was found to be "acceptably low considering the natural history of the disease." The panel stated that a surgeon should be involved from the outset in the team caring for patients with bleeding peptic ulcers.

A consensus was reached that therapeutic endoscopy should be directed at selected high-risk patients. "A clinical feature of high risk for rebleeding or death," the panel said, "is rapid bleeding with substantial blood loss manifested by hemodynamic instability, ongoing transfusion requirement, red hematoma, or red stool." Also at high risk, the panel said, are patients older than 60 years, or with associated diseases, or whose bleeding begins in the hospital, or who rebleed there.

Specific indications for therapy were suggested by the panel, which stated, "There is consensus that the findings of pulsatile bleeding (spurring) or oozing from the ulcer are indications for treatment. In addition, the finding of a pigmented protuberance ('visible vessel' or 'sentinel' clot) in the ulcer crater is an indication for endoscopic therapy."

The statement recommended several scientific initiatives that deserved priority, including continuing evaluation of techniques and standardizing the use of terms such as visible vessel, adherent clot and persistent and recurrent bleeding. In addition, the panel recommended quantitating the risk of serious bleeding or rebleeding as relates to endoscopic features and host clinical factors. Other efforts that the panel recommended were defining optimal treatment regimens and exploring improved diagnostic and therapeutic technologies with biomedical engineers.

Free single copies of the complete statement are available from the Office of Medical Applications of Research, Bldg. 1, Rm. 260, phone 496-1143. □
Electrician and 'Guru' Spence Retires

By Anne Barber

Called the "guru of Bldg. 10's electrical system" by his supervisors, Donald Spence has retired after 36 years of government service. Twenty-eight of those years were spent at NIH; 22 working in Bldg. 10. His official title was electrician leader in the Clinical Center's maintenance section, Division of Engineering Services.

"When I first joined Bldg. 10, they gave me the old electrical diagrams of the building," Spence says. "They were so outdated that it took me a long time to bring them all up-to-date."

"I have prided myself on learning everything about the electrical system in this building," he continued. "I even gave a lot of my own free time to accomplish this."

Lots of changes have taken place in Bldg. 10 since Spence arrived in March 1967.

"Nothing could compare to the beauty of the original building with the circular driveway," he says.

"I hope my work here has contributed to NIH's mission because NIH does such wonderful things and helps a lot of people," Spence said. "Even my own family." His father received treatment from NEI for his macular degenerative eye disease and his aunt had a biopsy performed here for breast cancer.

A believer in giving as well as receiving, Spence's favorite charity is the Patient Emergency Fund. "In fact," he says, "my unit has always supported the PEF by holding auctions among themselves long before the R&W association joined forces." Instead of sending Christmas cards to each other, members of the maintenance section contributed that money along with funds earned from white elephant sales held within their own shop.

In spite of always being on call for an emergency, day or night, Spence says, "I couldn't have worked in a nicer place. The people here have always been nice and friendly to me."

Although most of the work that Spence does is behind the scenes, he has managed to meet and talk with a few celebrities.

"I shook hands with former President Lyndon B. Johnson, met Hubert H. Humphrey, and had a chat with Edward Bennett Williams, former owner of the Washington Redskins," he said. "I also ran into Sen. Edward Kennedy once when we both got on the same elevator. He was alone and going to visit someone on the 12th floor."

"I have always been an electrician," he states. "When I was in high school, I worked for ABC Electrical Motor Repair. I served as an electrician apprentice at the U.S. Naval Weapons Plant before serving 8 years in the Air Force."

When the Navy Yard closed in 1961, Spence was given three choices of places to work—the Naval Ordnance Laboratory, David Taylor Model Basin, or NIH.

"When I came out to visit NIH and saw all the green hills, I thought this must be where they put you out to pasture. So I chose NIH," he said. "Thus far, I've been right."

Before joining Bldg. 10, Spence worked for 6 years in the electrical shop of Bldg. 13. During those years he worked all around the reservation and at the Poolesville animal facility as well.

"Biggest thing I'll miss is all my friends here," he says. "I've never gone into a building without seeing someone I know."

Spence will continue working in his trade as he and his wife, Linda, bought an old Victorian home (100 years old) in Prosperity, S.C. In fact, Linda, who retired from the CC director's office 2½ years ago, is already down there working on renovations.

They chose to live in Prosperity because Spence's dad was born there (the ancestral home still stands); most of his relatives still live in the area and have been there since the 1750's. His mother's relatives are also close by in Greenville.

Spence received many awards and certificates throughout his years of service at NIH. "While it certainly was nice to be recognized," he insists, "I was only doing my job." ☐

R&W Club Information Day

R&W is sponsoring a Club Information Day on Wednesday, Apr. 5 from 11:30 a.m. to 1:30 p.m. in the exhibit area of Bldg. 10. Come learn about the various club membership opportunities available through R&W. ☐

Introducing New NIH Kermit

The DCRT training program is sponsoring a Kermit seminar using the new Kermit 2.31. NIH on Apr. 14, 9–11 a.m., Bldg. 12A, Rm. B51.

Kermit is a software package used for uploading and downloading data between the mainframe computer and the PC. The new version of Kermit features an improved, fully automated installation procedure, improved terminal emulation, script language enhancements, larger file transfer packet size, and other new features that will be covered. The manual and software for the new version are available without charge.

To register for the seminar, contact the DCRT Training Unit, 496-2339, or TDD (telecommunication device for the deaf) 496-8294. There is no fee for the seminar and no formal application is required. ☐

NIH Travel Module

The NIH Travel Module has been developed by DCRT with the help of the Division of Financial Management (DFM). Pilot testing for phase one—Domestic Travel Order and Advance—began Feb. 21 and is running very smoothly. The NIAID and DCRT were the first BIDs in the pilot testing and have found this system to be most efficient for travelers, administrative personnel and the DFM. If your BID would like more information on the travel module, please contact Dennis George of DCRT, 496-6256. ☐
The NIH Training Center of the Division of Personnel Management offers the following:

**Courses and Programs**

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**TRAINING TIPS**

**Lay Lecture on Viruses**

"Viruses: How They Affect Us," the fourth and final lecture in the 1988-89 STEP program "Science for All" series, will be held on Thursday, Apr. 27, from 1 to 3 p.m. in Wilson Hall, Bldg. 1.

What is the difference between viruses and bacteria? Why can't viruses be treated with antibiotics? Why are there vaccines for some viruses and not for others? What is interferon, where does it come from, what are its uses? What are slow viruses; how do they differ from other viruses such as the cold viruses? Why are some viruses so deadly?

These and other questions about viruses will be answered by Dr. Phillip Grimley, professor in the department of pathology at the Uniformed Services University of the Health Sciences. He will discuss this topic, which affects all our lives, in easy-to-understand language and there will be ample time for questions from the audience.

All are encouraged to attend this event. Advance registration is not required nor is continuing education credit available. For additional information, contact the STEP program office, 496-1493.

**Dementia Costs Climb to $88 Billion, Says NIA Report**

By Marian Emr and Claire McCallough

Alzheimer's disease and related dementias may have cost close to $88 billion in 1985, according to analysis by NIA health econo­mists. The cost estimate is based on those patients who are 65 or older and suffer from Alzheimer's disease, multi-infarct dementia or mixed cases of both. This group accounts for about 85 percent of all dementias in the population. Alzheimer's disease represents approximately 60 percent of the total costs of the dementias considered in this study.

The analysis was carried out by NIA health economist Dr. William Cartwright and colleagues Dr. Lien-Fu Huang at Howard University in Washington, D.C., and Teh-wei Hu at the University of California, Berkeley.

According to the investigators, direct patient care costs, including nursing home care and social services, were $13.26 billion. This figure is conservative because it includes only the additional costs of care, or those above and beyond the average costs of medical care for other conditions not related to the dementing illness.

A recent study by the U.S. Office of Technology Assessment, Losing a Million Minds, reports that the government pays only 10 to 15 percent of costs for Alzheimer's disease, mostly for direct medical care, imposing a heavy burden on the affected families. According to Cartwright and his colleagues, dementia patients, unlike victims of other major killers, typically spend a number of years receiving care at home until the disease progresses to a point where institutionalization becomes necessary.

Most in-home care required by Alzheimer's patients is for custodial (nonmedical) care—supervision and assistance with daily tasks such as eating, bathing and dressing—and is not normally covered by government entitlement programs. The indirect cost of such home care, $31.46 billion (provided mainly by family members), is much higher than that for direct care. Another $43.17 billion of economic loss is due to loss of productivity during the extended period of illness and to premature death.

The investigators note that the total amount is conservative for a number of reasons, one being that it does not take into account the stress-related costs to caregivers and their families. Another reason that the figures are probably low, the investigators explain, is because they included in their analysis total costs for only the 3.5 percent of nursing home patients admitted for dementia. For most of the 50 percent, or more than 600,000, of nursing home residents thought to suffer from dementia, just the additional cost of care was counted.

Information on the costs of dementia is essential for the development of new social, health and economic policies for affected patients and their families, to determine research priorities, and for supporting aging and medical research.

**Volunteers Needed**

White females, 20-45 years of age, are needed for a National Institute of Dental Research saliva and oral sensory study. Time required is 1 1/2 hours and there are no invasive procedures. Volunteers must not be pregnant or taking any medications. Please call Beverly Handelman, 496-4371, if you have questions or are interested in participating.

**Donate Racquets for Kids**

Give a deserving youngster a chance to play tennis by donating your old, but still serviceable, racquet. Bring your racquet to the R&W Activities Desk in Bldg. 31-B1W30 or place it in the display outside the Gift Shop in Bldg. 31 or the Fitness Center, 31C-B4 level.

The American Tennis Industry Federation will see that the racquets collected by R&W will be given to beginning players. Receipts for the appraisal value of the racquet for a deduction on your income tax are available at the Activities Desk.
Stetten Museum Spotlights Three NIH Inventions

Medical instruments fuel the progress of medicine, helping doctors to diagnose and treat diseases and enabling researchers to study old problems in new detail and to ask new questions. "An Impact on the World: Three Instruments Invented at NIH," is a new exhibit mounted by the DeWitt Stetten, Jr. Museum of Medical Research. Located in the hallway leading to the Lipsett Amphitheater, Building 10, this exhibit focuses on three devices developed at NIH—the Rees micromanipulator, the ELISA reader, and the evening (toposcopic) catheter—why they were made, how they work, and their impact in connection with specific diseases.

The oldest instrument is a micromanipulator developed in 1937 by Dr. Charles W. Rees in NIH's Division of Zoology (now the Laboratory of Parasitic Diseases, NIAID). The micromanipulator was primarily employed to isolate the protozoa Entamoeba histolytica. E. histolytica normally lives harmlessly in the human gut until some mechanism, which is still unknown, causes it to turn into a killer. E. histolytica is one of the world's leading causes of death. Building on Rees's successful isolation of single protozoa for cultivation, Dr. Louis Diamond of NIAID developed a method for growing the protozoa without its attendant bacterial flora, enabling scientists to study E. histolytica in a pure culture. Although this micromanipulator is no longer used, the genealogically uniform cultures of E. histolytica prepared with it have become the largest such collection in the world, available for other researchers to use.

The ELISA reader was built by Thomas R. Clem, Sr., of the Biomedical Engineering and Instrumentation Branch, DRS, for Dr. Robert H. Yolken of NIAID in 1976-1977; it decreased the time technicians needed to read the newly developed enzyme-linked immunosorbent assay (ELISA) test. The ELISA test is a sensitive diagnostic tool for many illnesses. The manual model featured in the exhibit was to be a stand-in allowing Yolken to continue his research while Clem readied an automated model. The manual reader worked so well, cutting reading time from 90 to 5 minutes per microtiter plate, that Yolken decided he did not need an automated one. Since 1982, however, several commercial firms have put out automated readers based on this reading technique, aiding the spread of the ELISA test. The exhibit discusses the ELISA reader's role in diagnosing various gastrointestinal illnesses, which is a group that are the leading cause of death worldwide.

The third object in the exhibit is the evening (toposcopic) catheter. The idea of a catheter that does not slide against vessel walls but extends itself by unfolding, or evening, originated with two Israeli investigators. They had adapted the evening action from an instrument used to investigate the nooks and crannies in nuclear reactors into a device that transported a toposcope into the intestinal tract. At NIH, Dr. Robert L. Bowman of NHLBI demonstrated that such a catheter could be miniaturized for use in the human cardiovascular system. Dr. John L. Dippman, chief of the diagnostic radiology department in the Clinical Center, was enthusiastic about the idea and supported the catheter's development and testing. Dr. Seth Goldstein and Daniel Shook, both of BEIB, surrounded various engineering problems to produce an instrument capable of navigating narrow and crooked vessels that other catheters cannot pass. The evening catheter, with its diagnostic and therapeutic potential, is just beginning to be marketed commercially.

The Rees micromanipulator, ELISA reader and evening catheter are only three of the instruments invented at NIH.

Michele Canham, a master's degree candidate in the museum studies program at George Washington University and an intern at the Stetten Museum, was guest curator for this exhibit. For additional information about the exhibit, contact Dr. Victoria A. Harden, curator of the museum, 496-6610.

Lectures on Future of Science

A free lecture series, "Science for the 21st Century," sponsored by Johns Hopkins University's Montgomery County Center on Medical Center Drs., Shady Grove, includes two talks of possible interest to NIH'ers. On Apr. 27, Dr. Michael Shara, an astronomer in the university's Space Telescope Science Institute, will speak on "Probing the Edge of the Universe: Space Observations in the 21st Century." Psychology professor Alfonso Caramazza will speak on "The Mind/Brain: The New Frontier of Science," May 18. Both lectures begin at 7:30 p.m. and are open to the public. For more information call 294-7040.