association of american medical colleges

MEETING SCHEDULE
COUNCIL OF ACADEMIC SOCIETIES
ADMINISTRATIVE BOARD

September 21 1983

5:00 p.m.	CAS Administrative Board Meeting Institute of Medicine Study of the NIH Guests: James D. Ebert, Ph.D. Chairman, Committee for the Study of the Organizational Structure of the NIH Michael A. Stoto, Ph.D., Study Director (See page 14)	Jackson Room
7:00 p.m.	CAS Reception	Kalorama Room
7:45 p.m.	CAS Dinner	Jackson Room
9:00 p.m.	Special Preview Showing: Videotape of keynote address at Houston seminar on "The Medicare Prospective Payment System: Implications for the Medical Schools and Faculties" (See enclosed flier)	Map Room

September 22, 1983

9:00 a.m.	CAS Administrative Board Meeting	Kalorama Room
1:00 p.m.	Joint Administrative Boards Luncheon	Lincoln West Room
2:30 p.m.	Adjournment	

Suite 200/One Dupont Circle, N.W./Washington, D.C. 20036/(202) 828-0400

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AGENDA
COUNCIL OF ACADEMIC SOCIETIES
ADMINISTRATIVE BOARD

I. Report of the Chairman

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MINUTES
COUNCIL OF ACADEMIC SOCIETIES
ADMINISTRATIVE BOARD

June 29-30, 1983
Washington Hilton Hotel
Washington, D.C.

PRESENT: Board Members

Frank C. Wilson, Chairman Presiding
Bernadine H. Bulkley
William F. Ganong
Robert L. Hill
Joseph E. Johnson, III
Douglas E. Kelly
Virginia V. Weldon

ABSENT:

David M. Brown
David H. Cohen
Lowell M. Greenbaum
John B. Lynch
Frank G. Moody

Staff

James Bentley*
John A. D. Cooper*
James Erdmann*
Charles Fentress*
Thomas Kennedy*
Joseph Keyes*
Lynn Morrison
Ann Scanley
John Sherman*
Emanuel Suter*
August Swanson
Lucy Theilheimer
Xenia Tonesk*
Kat Turner*

GUESTS:

Donald Langsley
Thomas E. Malone*
Thomas K. Oliver
William F. Raub*
S. Stephen Schiafino*
Richard Wilbur

The CAS Administrative Board convened on June 29 at 5:00 p.m. to discuss a proposed statement of principles on the NIH. In addition, Dr. Thomas Kennedy of the AAMC provided a status report on the NIH reauthorizing legislation and FY 1984 appropriations. The meeting adjourned at 7:00 p.m. for a social hour followed by dinner at 7:45 p.m. The CAS Board reconvened at 9:00 a.m. on June 30 for a business meeting and a discussion regarding peer review with officials from NIH. The Board joined the other Administrative Boards for a joint luncheon meeting at 12:30 p.m.

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* present for part of the meeting

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I. APPROVAL OF MINUTES

The minutes of the April 20-21, 1983 CAS Administrative Board meeting were approved as submitted.

II. ACTION ITEMS - CAS Board

A. Membership Application

Drs. Johnson and Ganong had been asked to review the application of the American Psychiatric Association for membership in CAS. Both recommended that the application be approved.

ACTION: The CAS Administrative Board voted to approve the application for CAS membership.

B. Distinguished Service Membership Nominations

By previous action of the CAS Board, it had been agreed that an individual is eligible for nomination to the category of distinguished service membership if he/she has served as chairman of the CAS, chairman of the AAMC representing the CAS, or as a member of the CAS Board for two consecutive terms.

ACTION: The CAS Administrative Board voted to nominate Daniel X. Freedman (CAS Chairman, 1980-81) and Thomas K. Oliver (CAS Chairman, 1978-79; AAMC Chairman, 1981-82) to the category of distinguished service membership in AAMC.

III. ACTION ITEMS - Executive Council

A. Payment for Physician Services in a Teaching Setting

Dr. James Bentley of the AAMC department of teaching hospitals provided background information on new Medicare regulations regarding payment for physicians' services. He stated that special payment rules for services provided in teaching settings were being developed. Therefore, the AAMC Committee for Payment for Physician Services in Teaching Hospitals had directed staff to develop a report including: 1) the history of teaching physician payment, and 2) policy options available to the AAMC to assure that physicians in teaching and non-teaching settings are paid comparable Medicare fees. The CAS Board reviewed the report and was asked for its recommendations regarding the most appropriate AAMC policy.

ACTION: The CAS Administrative Board approved the report for distribution to Administration officials and Congressional staff. The Board also endorsed AAMC efforts to assure that Medicaid payments are excluded from the calculation of customary charges upon which Medicare reimbursements are based. In addition, noting that the new regulations may be particularly onerous for some institutions in Pennsylvania, the Board recommended that the AAMC play a supportive role to these schools as they attempt to address their local difficulties.

B. Plan of Action for Dealing with PGY-2 Match Issues

At the April Executive Council meeting, problems related to the matching of residents were discussed. Following up on that discussion, AAMC staff had considered the extent to which program directors in some specialties select senior students into PGY-2 positions--a practice incompatible with the National

Resident Matching Program. This early selection also forces the student to make premature decisions regarding specialty choice, often disrupting the student's fourth year.

Joseph A. Keyes of the AAMC staff reported that a letter had been sent from Dr. Cooper to the presidents of 18 CAS-member societies of program directors soliciting their views regarding this issue. The matter had also been placed on the agenda for the July meeting of the Council for Medical Affairs. As a future course of action, it was recommended that: 1) staff analyze the responses to Dr. Cooper's initial inquiry; 2) efforts be made to identify specific problems related to the matching of residents as well as possible solutions; 3) recommendations be developed regarding the PGY-2 issues which might be agreeable to the AAMC, the NRMP and the specialties in question; and 4) efforts continue to be made to involve others in the consideration of these issues.

ACTION: The CAS Administrative Board approved the recommendations for dealing with the PGY-2 match issues.

C. Loan Forgiveness for Physicians in Research Careers

At the April Board meeting, Dr. Thomas K. Oliver, immediate past chairman of the AAMC, had presented a proposal to establish a Federal program to forgive the indebtedness of young physicians who pursue research careers. The CAS Board had endorsed the proposal with a few modifications. Because the COD and COTH Administrative Board had not considered the proposal in April, Executive Council consideration of the issue had been deferred.

ACTION: The CAS Administrative Board reaffirmed its previous position and recommended that a strong effort be made to secure enactment of legislation which would implement a loan forgiveness program.

D. Determining the Resident-to-Bed Ratio for Purposes of Medicare Reimbursement

The recently enacted Medicare Prospective Payment System includes an adjustment in payment rates based upon a hospital's resident-to-bed ratio. Dr. James Bentley reported that the adjustment provides a 12.13% increase in per case payments for every 0.1 resident per bed. This provision poses a critical question regarding how residents are to be counted in order to compute a hospital's resident-to-bed adjustment. In discussing this issue the Board considered the following:

- Residents have been determined by the National Labor Relations Board to be students and not employees.
- Calculations are to be based on a 35-hour work week--a low estimate of the number of hours most residents spend in a hospital.
- The provision is based on a count of individuals rather than positions.
- It is unclear whether subspecialty fellows should be counted as residents.

The Board was asked to consider whether AAMC staff should meet with officials from the Health Care Financing Administration and Congressional staff to discuss these issues and recommend that:

- The number of FTE residents be determined on the basis of the resident's assigned training time with one FTE equal to 12 man-months of training,

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- In the case of residents assigned to more than one hospital, unassigned time should be allocated among the hospitals proportionately,
- Clinical fellows, senior residents, and other advanced trainees should be included in calculations of the number of residents if they do not bill for patient care services,
- Residents assigned to non-provider training settings should not be included in the count for the period assigned outside the hospital.

ACTION: The CAS Board endorsed the recommendations with the suggestion that "fellows" be described as "advanced trainees."

E. ACCME Protocol for Recognition of State Medical Societies as Accreditors of Intrastate CME Sponsors

Dr. Emanuel Suter of the AAMC staff reviewed action taken at the January Executive Council meetings regarding the ACCME "protocol." It had been recommended that the AAMC propose two modifications: 1) that the Committee for Review and Recognition of State Medical Societies (CRR) should include three members nominated by the ACCME parent organizations, and 2) that the ACCME should have the opportunity to review CRR decisions.

Since that time, the ACCME had agreed to accept the AAMC's first recommendation. However, the second recommendation had not been approved. The Board was asked to consider acceptance of this compromise adopted by the ACCME.

ACTION: The CAS Administrative Board voted to approve the "protocol" as amended by the ACCME.

F. ECFMG Constitutional Issues

Dr. Suter reported on several constitutional changes being considered by the Educational Commission for Foreign Medical Graduates (ECFMG). It had been proposed that trustees be elected by the ECFMG Board from nominees submitted by the sponsoring organizations. Currently, sponsoring organizations appoint representatives directly to the Board. It was agreed that the policy change might weaken the relationship between the ECFMG and its sponsoring organizations.

ACTION: The CAS Administrative Board agreed that changes to the bylaws which would alter the nomination process as stated above should be opposed.

IV. DISCUSSION ITEMS - CAS Board

A. Dr. William F. Raub, director for extramural research and training at NIH; Dr. Thomas E. Malone, deputy director of NIH; and Dr. S. Stephen Schiafino, deputy director of the NIH division of research grants, joined the Board for a discussion of the NIH peer review system. Specifically, the Board and the NIH staff had an informal discussion of how the work of study sections is fairing under current fiscal pressures.

Dr. Raub presented statistics which revealed extramural funding trends. He stressed the fact that support of the extramural research grant program had been and would continue to be a major priority for the NIH. In order to assure stable funding for R01s, monies have been shifted from training, contracts, and other grant programs (see Addendum 1). Dr. Raub also discussed

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some concerns regarding the function of peer review groups: the overwhelming workload; the difficulty of recruiting qualified individuals to serve on peer review panels; and the increasing number of rebuttals to study section recommendations--due in large part to the intense competition for fewer research dollars.

In discussing the composition of study sections, it was emphasized that there is an effort to assure representation of women and minorities. However, the Board expressed concern regarding the need to assure a balance of basic scientists and clinical investigators on review panels. The Board also pointed out that there are many outstanding scientists who have never been asked to serve. It was agreed that the AAMC should attempt to assist NIH staff by encouraging CAS societies to nominate individuals to serve on study sections.

B. Extension of the AAMC Clinical Evaluation Project

Dr. Xenia Tonesk of the AAMC staff provided background on the clinical evaluation project. In the implementation phase of the project, it became clear that in order to improve the evaluation system in institutions, the clinical education continuum should be considered, extending through at least the first three years of graduate medical education. AAMC staff has considered approaches to the evaluation of students in clinical settings and hopes to work with a group of selected institutions to extend the project to assess the evaluation of residents.

Dr. Cooper pointed out that at an AAMC-sponsored resident conference held in 1981, considerable concern had been expressed about the ways in which resident performance is evaluated. Dr. Donald Langsley, executive vice president of the American Board of Medical Specialties, commented that the ABMS would welcome a study of the evaluation of residents. It was suggested that a major thrust of the expanded project should be consideration of the assessment of residents as evaluators and teachers.

It was reported that the AAMC Executive Committee had endorsed the extension of the project and had agreed that the Association should seek outside financial support for its continuation. The CAS Board concurred with this recommendation.

C. CAS Fall Meeting Plans

Lucy Theilheimer of the AAMC staff reported on plans for the November CAS meetings. A portion of the meeting will focus on the theme of, "Research Support: A Consensus is Needed." A panel discussion will include presentations by Dr. William Raub, SCIENCE reporter John Walsh, and former Robert Wood Johnson health policy fellow, Leonard Heller. It is hoped that the session will highlight the importance of unity within the research community regarding issues related to the NIH including the allocation of funding. Dr. Sherman Mellinkoff, dean of the UCLA School of Medicine, will present closing remarks.

The Board was asked to consider possible agenda items for the annual business meeting. After a brief discussion, it was agreed that a CAS presidents' breakfast should not be scheduled.

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V. DISCUSSION ITEM - Executive Council

A. Statement of Principles on NIH

At its April meeting, the Executive Council had discussed pending legislation to renew the expiring authorities for certain NIH programs. Staff was directed to develop a statement of principles which could be used to generate strong support for the NIH without the "micromanagement" of the Congress as exemplified by the pending legislation.

The Board reviewed two documents which had been prepared by staff. The intended audience was discussed and it was pointed out that a statement which is appropriate for dissemination within the academic community might not be appropriate for distribution to Administration officials, the Congress, or the general public. It was agreed that two documents should be developed: one to address the academic community and one for their use in interactions with policymakers. It was suggested that any implementation strategy should be a separate document for use as an internal guide. In terms of the content of the statements, it was agreed that they should be concise, "understandable," and as prospective as possible, rather than merely advocating past or current practice with regard to the administration of the NIH. The Board also suggested that current scientific opportunities should be emphasized as well as the successes of the past. Revised documents will be reviewed by the Boards at the September meetings.

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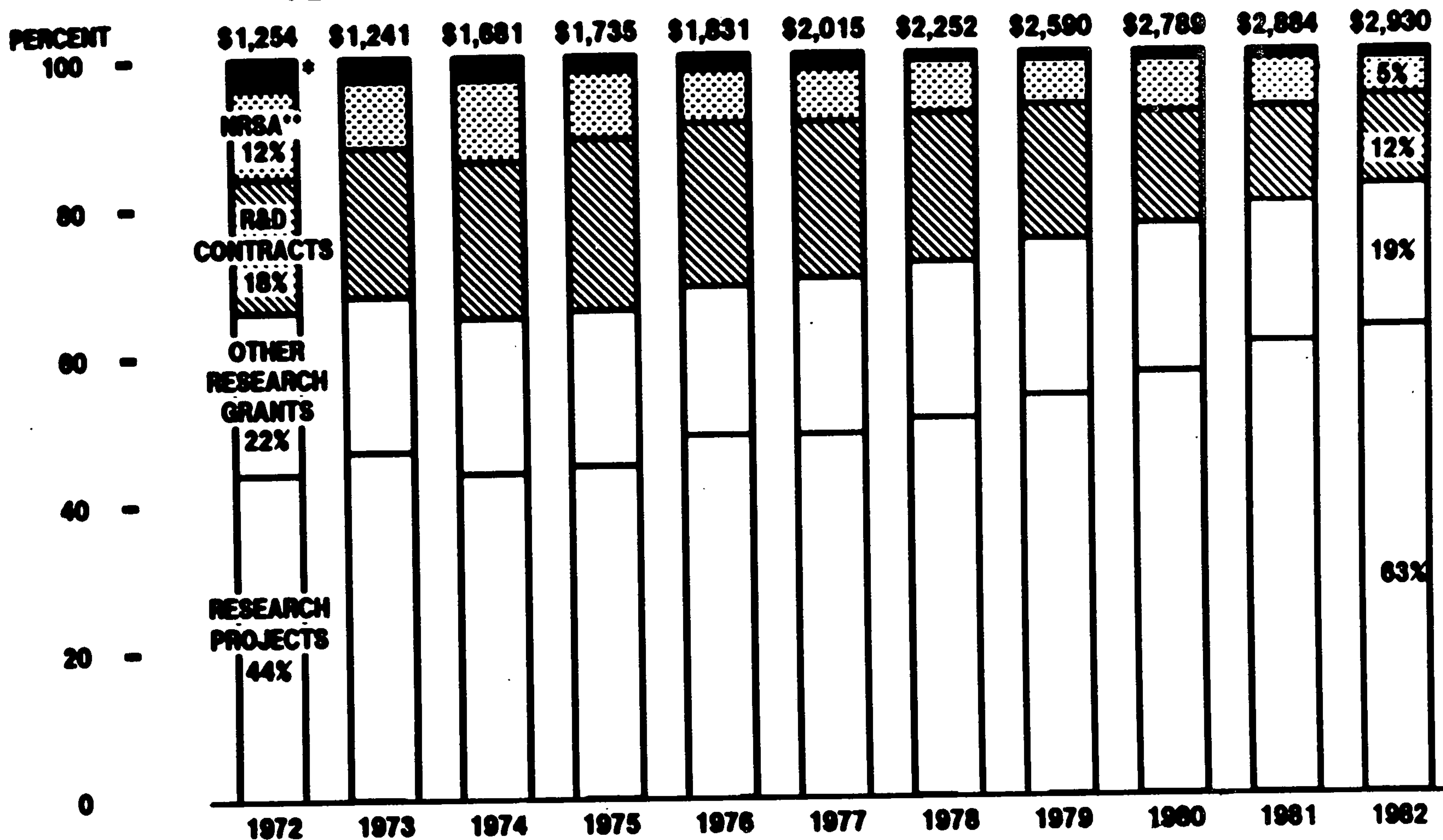

NOTE: SEE PAGE iii FOR ACTIVITY COVERAGE. EXCLUDES TQ. *INCLUDES GRANTS FOR CONSTRUCTION, CONTROL AND MEDICAL LIBRARIES. **INCLUDES PRE-NRSA TRAINING.

SOURCE: NIH, DRG, STATISTICS AND ANALYSIS BRANCH

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ADDENDUM 1

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MEMBERSHIP APPLICATION
COUNCIL OF ACADEMIC SOCIETIES
ASSOCIATION OF AMERICAN MEDICAL COLLEGES

MAIL TO: AAMC, Suite 200, One Dupont Circle, N.W., Washington, D.C. 20036
Attn: Ms. Lynn Morrison

NAME OF SOCIETY: American Association of Directors of Psychiatric Residency Training, Ir

MAILING ADDRESS: Executive Office: Institute of Living
200 Retreat Avenue
Hartford, CT 06106

PURPOSE: Please see attached Certificate of Incorporation and By-Laws.

1) To promote understanding and communication among representatives of psychiatric residency training programs; to assist in the attainment and maintenance of high professional and academic standards; to undertake studies relative to graduate psychiatric education, including social and economic aspects of residency training; and to disseminate and publish results of such studies for the benefit of and implementation by interested and concerned professional organizations.
2) To engage in any other lawful act or activity for which corporations may be formed under the Nonstock Corporation Act of Connecticut, etc.

MEMBERSHIP CRITERIA: There are three classes of membership (please see bylaws):
1) Institutional Members: Membership consists of psychiatric hospitals and departments of psychiatry and/or child psychiatry of other institutions which maintain accredited programs of psychiatric residency training; 2) Individual Members: Board eligible psychiatrists; 3) Honorary members.

NUMBER OF MEMBERS:
292

NUMBER OF FACULTY MEMBERS:
292

DATE ORGANIZED: 10/1/73

SUPPORTING DOCUMENTS REQUIRED: (Indicate in blank date of each document)

10/1/73 - original bylaws
5/2/83 - amended bylaws (enclosed) 1. Constitution & Bylaws

1/83 2. Program & Minutes of Annual Meeting

(CONTINUED NEXT PAGE)

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QUESTIONNAIRE FOR TAX STATUS

1. Has your society applied for a tax exemption ruling from the Internal Revenue Service?

   __XX__ YES ______ NO

2. If answer to (1) is YES, under what section of the Internal Revenue Code was the exemption ruling requested?

   509(a)(2); 501(c)3

3. If request for exemption has been made, what is its current status?

   x a. Approved by IRS

   ___b. Denied by IRS

   ___c. Pending IRS determination

4. If your request has been approved or denied, please forward a copy of Internal Revenue letter informing you of their action.

Charles Boren
(Completed by - please sign)
(Charles W. Boren, M.D.)
Executive Secretary

July 27, 1983
(Date)

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MEMBERSHIP APPLICATION
COUNCIL OF ACADEMIC SOCIETIES
ASSOCIATION OF AMERICAN MEDICAL COLLEGES

MAIL TO: AAMC, Suite 200, One Dupont Circle, N.W., Washington, D.C. 20036
Attn: Ms. Lynn Morrison

NAME OF SOCIETY: The American Society for Cell Biology

MAILING ADDRESS: 9650 Rockville Pike, Bethesda, MD 20814

PURPOSE: The purpose of the Society is to promote and develop the field of Cell Biology.

MEMBERSHIP CRITERIA: Membership is open to scientists who share the stated purpose of the Society and who have educational or research experience in Cell Biology.

NUMBER OF MEMBERS: 5,000

NUMBER OF FACULTY MEMBERS: 4,000

DATE ORGANIZED: 1961

SUPPORTING DOCUMENTS REQUIRED: (Indicate in blank date of each document)

1983 1. Constitution & Bylaws

1982 2. Program & Minutes of Annual Meeting

(CONTINUED NEXT PAGE)

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QUESTIONNAIRE FOR TAX STATUS

1. Has your society applied for a tax exemption ruling from the Internal Revenue Service?

   X YES ______ NO

2. If answer to (1) is YES, under what section of the Internal Revenue Code was the exemption ruling requested?

   501-C-3

3. If request for exemption has been made, what is its current status?

   ___a. Approved by IRS

   ___b. Denied by IRS

   ___c. Pending IRS determination

4. If your request has been approved or denied, please forward a copy of Internal Revenue letter informing you of their action.

O. S. Young
(Completed by - please sign)

8/12/83
(Date)

FALL MEETING PLANS

As discussed at the June Board meeting, the November 6 session of the CAS Fall Meeting will focus on the theme, "Research Support: A Consensus is Needed." The November 6 program is as follows:

Research Funding Priorities of the National Institutes of Health

William F. Raub, Ph.D.
Associate Director for Extramural Research, NIH

Statement of Basic Principles of the Nation's Medical Research Program

John F. Sherman, Ph.D.
Vice President, AAMC

Congressional "Micromanagement" of the NIH

John Walsh
Reporter for News and Comment, SCIENCE

The Science of Politics and the Politics of Science

Leonard Heller, Ph.D. (former Robert Wood Johnson Foundation Health Policy Fellow)
Vice Chancellor for Academic Affairs, University of Kentucky Medical Center

Can Biomedical Research Survive Attacks of Confused Lucidity?

Sherman M. Mellinkoff, M.D.
Dean, UCLA School of Medicine

A CAS reception will conclude the day's activities on November 6.

On the afternoon of November 7, the annual CAS Business Meeting will be held including the election of the administrative board and new members. The usual legislative update will be provided. In addition, Dr. Hill, as chairman of the National Research Council's Committee on a Study of National Needs for Biomedical and Behavioral Research Personnel, will make a brief presentation regarding the Committee's findings and recommendations. Updates will also be provided regarding the General Professional Education of the Physician Project, the AAMC Clinical Evaluation Project, the Institute of Medicine's study of the organizational structure of the NIH, and the implications for faculty of the Medicare prospective payment system.

The Board should consider other possible topics for discussion at the November 8 business meeting.

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1984 INTERIM MEETING PLANS

In recent years, as efforts have been made to assemble a coalition of organizations on specific issues (e.g., the NIH budget), it has become evident that the officers of many CAS member societies are not involved in or even aware of AAMC activities. In addition to this ineffective liaison with AAMC, it is clear that the officers of these organizations have not established efficient mechanisms for contacting their members in a timely manner regarding important issues. To address these problems, the CAS Board might consider the possibility of a meeting in the spring of 1984 for CAS presidents, public affairs representatives, and executive directors (where applicable). Of course, the official CAS representatives also would be welcomed to attend. One purpose of the meeting would be to discuss ways of improving: 1) the liaison between the society officers and the AAMC, and 2) methods of communication between the officers and members of societies. Any staff recommendations regarding the latter would take into account the varying sizes and purposes of the organizations. Topics for discussion at the meeting could include the Administration's 1985 budget as well as the need for consensus regarding the support of research, with particular attention to the issues raised in the final version of the statement of principles on page 46 of the Executive Council agenda.

The Board should discuss options regarding the interim meeting:

- a meeting as described above
- a meeting of the official CAS representatives on another topic
- no meeting in 1984

One possible date for the meeting would be April 10-11, immediately preceding the Administrative Board meeting.

IOM STUDY OF THE NIH ORGANIZATIONAL STRUCTURE

The National Academy of Sciences, Institute of Medicine has begun a study of the organizational structure of the National Institutes of Health. Former HHS Secretary Richard Schweiker initiated the study in response to increasing public and political pressure to alter or expand the current NIH structure. The purpose of the study is: 1) to develop criteria to be used when assessing the need to make any substantial organizational changes, and 2) to consider possible alternatives to the current NIH structure. No doubt, the study's recommendations will have a major impact on the extent to which the public and the Congress will determine the program directions of the NIH.

An IOM committee has been appointed to conduct the study under the chairmanship of Dr. James D. Ebert, president of the Carnegie Instution of Washington.* In addition, separate panels will be formed to consider historical issues relating to the organizational structure of NIH, the current structure, and possible alternative structures. To aid the committee and panels, public hearings will be held on September 26-27 to allow the opportunity for organizations and individuals to offer their views. The AAMC has been invited to participate (see following page) and will submit testimony. In addition, CAS presidents were notified of the study and encouraged to submit written comments.

Dr. Ebert and the committee staff, Dr. Michael A. Stoto, will join the CAS and COD Administrative Boards Wednesday evening at 6:00 pm for an informal discussion of the IOM study.

* The full Committee list appears on page 17.

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NATIONAL ACADEMY OF SCIENCES
2101 CONSTITUTION AVENUE
WASHINGTON, D. C. 20418

INSTITUTE OF MEDICINE

August 1, 1983

John A. D. Cooper, M.D.
President
Association of American Medical
Colleges
One Dupont Circle, NW
Washington, DC 20036

Dear John:

In May, Dr. Frederick Robbins wrote to your organization to report on the initiation of an IOM study on the Organizational Structure of the National Institutes of Health, and to solicit candidates for the committee and for panels that will be appointed to assist the committee. I write now to inform you of the committee's progress and to invite you to participate in public hearings about the organization of NIH.

Most of the committee has already been chosen (a roster is enclosed), and it held its first meeting in Washington on June 28 and 29, 1983. At this meeting, the committee decided to form panels to investigate historical issues relating to the organizational structure of NIH, the current structure for making decisions and setting priorities, and possible alternative structures for priority setting. These panels will each be chaired by a member of the main committee and have four or five other members. They will meet for the first time in late September or early October. In choosing the committee, we have taken the suggestions of many professional societies and health organizations. We will continue to do so in choosing the panel members.

To aid the panels and the main committee in their investigations, we are planning two days of public hearings and discussions about the organizational structure of NIH. These will take place on September 26 and 27, 1983, in the Lecture Room of the National Academy of Sciences. In particular, the committee wishes to receive testimony about:

1) the effect of organizational changes in the last fifteen years on the flow of funds into various fields, on the management and coordination of biomedical research, and on the comprehensiveness and quality of research in the affected fields;

2) the strengths and weaknesses of the current organizational structure of disease-based institutes, advisory councils, peer-review groups, and so on, for managing and ensuring high quality and relevant biomedical research; and

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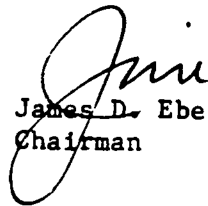
3) the strengths and weaknesses of possible alternative organizational structures, particularly as exemplified by existing research organizations.

To facilitate a focused discussion, we invite all interested parties to submit brief written statements of their views. Based on the written statements, we will choose a small number of speakers to lead a panel discussion on each of the above topics. Others will be welcome to participate in the discussions from the floor. Both the written comments and a summary of the panel discussions will form an important part of the information base for the panels and the main committee. Because they ensure an accurate representation of your views, the committee especially values written comments.

In order to be considered for leading one of the panel discussions, or to be a participant, please send written comments to Michael A. Stoto, Ph.D., the study director, by September 6th. Other written comments should be received by October 1st to get the full consideration of the committee and panels. Please call Dr. Stoto or Cindy Howe at 202/334-2268 if you plan to attend, or for further information.

Sincerely yours,



James D. Ebert, Ph.D.
Chairman

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association of american medical colleges

JOHN A. D. COOPER, M.D., PH.D.
PRESIDENT

September 6, 1983

202: 828-0460

Ms. Betty Lou Dotson
Director
Office of Civil Rights
Department of Health and Human Resources
330 Independence Avenue, S. W., Rm. 5400
Washington, D. C. 20201

RE Proposed Rule: Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants

Dear Ms. Dotson:

On behalf of the members of the Association of American Medical Colleges, I am writing to express our grave displeasure with the revised version of the regulation addressing the provision of health care to handicapped infants published on July 5, 1983. A federal district court judge nullified the original regulation, calling it "arbitrary and capricious" and "a hasty and ill considered (method of addressing) one of the most difficult and sensitive medical and ethical problems facing our society." After such an admonishment, it is distressing to find that the Department of Health and Human Services could reissue the regulations virtually unchanged. The implication in the regulation, particularly in the preamble, that health care providers callously allow handicapped children to die from lack of treatment or nutrition is offensive to all health care providers and particularily to those who have devoted their professional lives to caring for sick children.

Just a few decades ago, most sick newborns died within a few hours of birth and premature infants were not expected to live more than a few days. Through the efforts of many health care professionals, the prognosis for these infants has changed radically. The many technological advances and the new skills in neonatology substantially have reduced the mortality rate for the severely ill and premature infants. In fact, since 1970 infant mortalities have been halved.

It is ironic that the professionals that make it possible for infants with critical problems to have a chance at life are treated in a proposed federal regulation as if they would habitually disregard a handicapped infant's needs. This assumption is false. Hospitals and their medical staffs provide care for all patients to the best of their ability. Teaching hospitals have a particular commitment to patients in need of critical care, including the infants that are the subject of this regulation. At the 350 nonfederal teaching hospital members of the AAMC, there were more than 720,000 births in 1980. More than three-quarters of these teaching hospitals provide premature nurseries and more than 70 percent have neonatal intensive care units.

Additionally, teaching hospitals and the medical schools with which they are associated train new physicians and engage in new areas of research to perpetuate and enhance their ability to care for critically ill infants.

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Traditionally, the parents and the physicians have made the very difficult decisions regarding the treatment that should or should not be rendered to children with life-threatening conditions. While some may disagree with the choice made in some of the cases, it should be recognized that the parents and physicians believed themselves to be acting in best interests of the child. The questioned raised by the case of Infant Doe and the resultant public outcry is how can the public voice its opinion regarding what is in the best interests of the child, presuming that this public voice would be less likely to concern itself with any physical or mental handicap of the child, or with the costliness of rendering continuous treatments to a child so handicapped.

The Department of Health and Human Services' answer to this question is that there ought to be an "alarm system" comprised of posted notices and toll free hot lines by which anonymous tipsters can summon teams of representatives from state child protection agencies and/or the Office of Civil Rights. This proposed approach is seriously flawed for several reasons:

- In the event there is a case in which a child is wrongfully denied treatment or nutrition, the HHS approach provides no assurance that the authorities would be called in time to take steps to protect the child.

- It is highly likely that this approach will result in a number of hospitals and physicians being falsely accused of inappropriately withholding treatment or nutrition. The few weeks in which the first "Baby Doe" regulation of the Department was in effect provided ample evidence that such false accusations would occur. These false accusations can be made either by well intentioned but uninformed people or by crank callers who may seek to harass the institutions or physicians involved.

- Perhaps the most disturbing consequence of the Department's proposed rule is the affect this method has on other infants. For example, during the period in which the original rule was in effect, an investigation was made on a "hot line" tip that Siamese twins at Strong Memorial Hospital in Rochester, New York were not receiving adequate care. This tip prompted the Office of Civil Rights to intercede. While everything possible had been done for the twins, the investigation and the investigators' lack of knowledge of the appropriate procedures to follow in conducting this inquest delayed the return of these infants to their mother. The mother, who was recovering in a nearby community hospital, was thus denied access to her infants during a significant portion of those few days they survived. The furor caused by the presence of the investigatory team and the newspaper accounts of the incident disturbed the parents of another infant so greatly that they removed their child from Strong Memorial before its treatments had been completed, thus jeopardizing its health.

- The investigations resulting from these false accusations are disruptive and time consuming and, most importantly, impair the hospital's ability to provide proper care for all of the infants in

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its nurseries by usurping the time of the medical and nursing staff that would otherwise be spent in rendering care.

- Posted notices, whether they are scattered about the units or located in the nurses' station, are seen by the families of children whose care is in no way being questioned. Those families may incorrectly infer from the notice that the hospital or some of the physicians have wrongfully withheld treatment on previous occasions. This inferrence would unnecessarily increase the family's anxiety when it is already under a great deal of stress. In addition to the stress to the parents, the staff of these units are demoralized by the signs and by the parents' reaction to the signs.

- By involving the state child protection agencies in the investigation of such cases, the proposed rule would seriously drain the already inadequate resources of these agencies and involve them at a time when they can lend no expertise in deciding the best course for treatment of the child. A more appropriate time for involving such agencies would be once a decision has been made that the child is treatable, but the parents refuse to allow the treatment. Then, the state child protection agencies would be acting as they might for a child of Jehovah's Witnesses to secure the rights of the child to treatment.

It is time a more thoughtful approach to this matter was seriously considered. After much deliberation and study of the issues involved, the President's Commission on Ethical Behavior in Medicine and Biomedical and Behavioral Research recommended the establishment of ethics review boards within each institution or community to address all cases involving persons of any age group in which a decision to forego life substaining treatment must be made. Several representatives of health care provider organizations have tailored this ethics review board concept to address these cases, and the resultant Infant Bioethical Review Committees (IBRCs) are described in the proposed amendment to the Medicare Conditions of Participation submitted with the comments of the American Academy of Pediatrics. This approach offers several advantages:

- All cases of infants for whom a decision must be made regarding the provision of life sustaining treatment will be addressed by the IBRC either through determination of a hospital policy or review of the individual cases.

- The alternatives for the child can be thoroughly discussed, including the help available for people with the same disabling condition as the infant.

- The review would occur as part of normal hospital procedure for such cases, thereby minimizing the disruption of services to other seriously ill infants. Also, because the review is required for all such cases, no inferences will be made that the treatment rendered by the physician(s) and health care team involved is faulty.

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- Notice of the existence and function of the IBRC can be made in such a way as to not alarm the families of infants whose care is not in question; further, the deliberations of the IBRC on a particular case shall be made in confidence, which also will minimize the anxiety to the other parents.

- Finally, the recommendation that we are advancing would be issued under the authority of the Secretary to set conditions for participation and avoids problems associated with reliance on Section 504 which is of dubious applicability.

We strongly urge you to consider withdrawing your proposed regulation and to substitute the proposal to establish IBRCs. If my staff or I may be of further assistance in helping you to consider this matter, please contact me at (202) 828-0460.

Sincerely,
Original signed by
J. A. D. COOPER, M.D.

John A. D. Cooper, M.D.

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APPENDIX

CONDITION OF PARTICIPATION:
Infant Bioethical Review Committee
Proposed 42 C.F.R. §482.___

The governing body must appoint an infant bioethical review committee (IBRC) or must join with one or more other hospitals to create a joint IBRC for the purposes of:

(1) providing advice when decisions are being considered to withhold or withdraw from infants life-sustaining medical or surgical treatment;

(2) recommending institutional policies concerning the withholding or withdrawal of medical or surgical treatments to infants, including guidelines for IBRC action for specific categories of life-threatening conditions affecting infants; and

(3) reviewing retrospectively infant medical records in situations in which life-sustaining medical or surgical treatment has been withheld or withdrawn.

A. Standard: Organization and Staffing.

The IBRC shall consist of at least 8 members and include the following:

(1) a practicing physician (e.g., a pediatrician, a neonatologist, or a pediatric surgeon)
(2) a hospital administrator
(3) an ethicist or a member of the clergy
(4) a representative of the legal profession (e.g., judge)
(5) a representative of a disability group, developmental disability expert, or parent of a disabled child
(6) a lay community member
(7) a member of the facility's organized medical staff
(8) a practicing nurse

The hospital shall provide staff support for the IBRC, including legal counsel. The IBRC shall meet on a regular basis, or as required under subsection B(3), below. It shall recommend to the steering committee of the medical staff and the governing board such administrative policies as terms of office and quorum requirements.

The IBRC shall recommend procedures to ensure that both hospital personnel and patient families are fully informed of the existence and functions of the IBRC and its availability on a 24-hour basis.

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B. Standard: Operation of IBRC.

1. Prospective policy development.

The IBRC shall develop and recommend for adoption by the governing body institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions. These shall include guidelines for management of specific types of cases or diagnoses, e.g., Down's Syndrome and spina bifida, and procedures to be followed in such recurring circumstances as, e.g., brain death and parental refusal to consent to life-saving treatment. The governing body, upon recommendation of the IBRC, may require attending physicians to notify the IBRC of the presence in the facility of an infant with a diagnosis specified by the IBRC, e.g., Down's Syndrome and spina bifida.

In recommending these policies and guidelines, the IBRC shall consult with medical and other authorities on issues involving disabled individuals, e.g., neonatologists, pediatric surgeons, county and city agencies which provide services for the disabled, and disability advocacy organizations. It shall also consult with appropriate committees of the medical staff, to ensure that the IBRC policies and guidelines build on existing staff by-laws, rules and regulations concerning consultations and staff membership requirements. The IBRC shall also inform and educate hospital staff on the policies and guidelines it develops.

2. Retrospective record review.

The IBRC, at its regularly-scheduled meeting, shall review all interim records involving withholding or termination of medical or surgical treatment to infants consistent with hospital policies developed pursuant to this condition, unless the case was previously before the IBRC pursuant to subsection B(3), below. If the IBRC finds that a deviation was made from the institutional policies in a given case, it shall conduct a review and report the findings to the steering committee of the medical staff and hospital board for appropriate action.

3. Review of specific cases.

In addition to regularly-scheduled meetings, interim IBRC meetings shall take place under specified circumstances to permit review of individual cases. The hospital shall require in each case that life-sustaining treatment be continued, until the IBRC can review the case and provide advice.

a. Convening of interim meetings.

(i) Interim IBRC meetings shall be convened within 24 hours when there is disagreement between the family of an infant

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and the infant's physician as to the withholding or withdrawal of treatment, or when a preliminary decision to withhold or withdraw life-sustaining treatment has been made, consistent with hospital policies developed pursuant to this condition.

(ii) Such interim IBRC meetings shall take place upon the request of any member of the IBRC or hospital staff or family member. The identity of persons making such requests shall remain confidential, and such persons shall be protected from reprisal. When appropriate, the IBRC or a designated member shall inform the requesting individual of the IBRC's recommendation.

(iii) The IBRC may provide for telephone and other forms of review when the timing and nature of the case, as identified in policies developed pursuant to B(1), make the convening of an interim meeting unfeasible.

b. Conduct of interim meetings.

Interim meetings shall be open to the affected parties. The IBRC shall ensure that the interests of the parents, the physician, and the child are fully considered; that family members have been fully informed of the patient's condition and prognosis; that they have been provided with a listing which describes the services furnished by parent support groups and public and private agencies in the geographic vicinity to infants with conditions such as that before the IBRC; and the IBRC shall facilitate their access to such services and groups.

c. Treatment effect.

In cases in which there is disagreement on treatment between a physician and an infant's family, and the family wishes to continue life-sustaining treatment, the family's wishes shall be carried out, for as long as the family wishes, unless such treatment is medically contraindicated. When there is physician/family disagreement and the family refuses consent to life-sustaining treatment, and the IBRC after complete information and due deliberation agrees with the family, the IBRC shall recommend that the treatment be withheld. When there is physician/family disagreement and the family refuses consent, but the IBRC disagrees with the family, the IBRC shall recommend to the hospital board that the case be referred immediately to an appropriate court or child protective agency, and treatment shall be continued until such time as the court or agency renders a decision or takes other appropriate action. The IBRC shall also follow this procedure in cases in which the family and physician agree that life-sustaining treatment should be withheld or withdraw, but the IBRC disagrees.

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C. Standard: Form and Retention of Records.

The IBRC shall maintain records of all of its deliberations and summary descriptions of specific cases considered and the disposition of those cases. Such records shall be kept in accordance with institutional policies on confidentiality of medical information. They shall be made available only upon court order, or to properly authorized staff of accrediting organizations or government agencies. In such instances, patient identification shall not be disclosed.

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