



E000495

MEMORANDUM

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service

HEALTH RESOURCES ADMINISTRATION
BUREAU OF HEALTH RESOURCES DEVELOPMENT

TO : Administrator, HRA
Through: Director, BHRD

DATE:

File

Acting Associate Director, Health Resources Planning, BHRD

FROM : Acting Director, DRMP

SUBJECT: Proposed Action on RMP Grant Applications for Planning and Development
of Pilot Arthritis Programs - ACTION

The business of the National Advisory Council for Regional Medical Programs at its meeting on June 13-14, included review and disposition of 43 RMP grant applications to carry out pilot activities in the field of arthritis. These applications are requests to participate in a \$4.5 million pilot arthritis initiative earmarked in the 1974 RMP appropriation. The 43 arthritis applications requested support totalling \$15.9 million against available earmarked funds, after a five percent Administration reserve, of \$4,275,000.

Council action was acceptance of recommendations of the Arthritis Ad Hoc Review Committee, which provided technical review of the arthritis grant applications on June 23, 24, and 25. The actions of the Committee were the following:

1. Approval for funding of Committee-modified programs in 31 RMP's for a total of \$4,730,860. (See Attachment A)
2. Establishment of criteria and principles of review toward achieving cohesive program, and to obtain best use of the limited, one-year funds. (See Attachment B, pp. 3-6) Outreach was emphasized for pilot development, while reviewers disparaged automated data, audio-visual, and wholly-public information activities.
3. Recommendations for coordination and evaluation of the National pilot arthritis initiative. (See Attachment B, pp. 6-7)

The National Advisory Council ratified the recommendations of the Ad Hoc Committee, and specifically recommended that the highest ranked programs through the Rank Score of 40 be supported with the earmarked arthritis funds (Attachment A). Council recommended that a way be found to support

approved, lower-ranked programs. While no vote was taken on this matter, it was suggested that the four (4) lower rank Regions be permitted discretion to fund approved arthritis activities when:

- a. the region can identify discretionary funds which it proposes to commit to the one-year approved programs; and,
- b. it obtains the approval of the Division of Regional Medical Programs to undertake the program.

Subject to your approval, we propose to carry out the recommended arthritis program.

Herbert B. Pahl, Ph. D.

Enclosures

Concur _____ Date _____ Nonconcur _____ Date _____

DEPARTMENT OF HEALTH EDUCATION AND WELFARE
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Arthritis Ad Hoc Review Committee
 Summary of Committee Recommendations
 (By Rank Score)

<u>Region</u>	<u>Rank Score</u> ^{1/}	<u>Total Requested</u>	<u>Recommended Total</u>	
Kansas	85	390,013	242,400	
Texas	85	356,559	244,200	
Arizona	80	241,638	215,000	
California	80	726,343	397,250	
Georgia	80	595,000	200,000	
Hawaii	80	461,820	216,000	
Mississippi	80	862,409	58,000	
Tri-State	80	844,775	213,370	
Wisconsin	80	267,857	62,000	
West Pa.	78	281,051	140,400	
Inter-Mtn.	75	385,463	169,500	
Michigan	75	823,413	194,700	
N. Dakota	75	340,800	111,000	
Arkansas	73	260,011	100,000	
New Mexico	73	272,765	163,600	
Alabama	70	272,360	228,400	
Grtr Del Val	70	385,001	247,500	
Ohio Valley	70	711,166	46,500	
Iowa	65	87,554	87,550	
N. Carolina	65	433,962	211,500	
Oklahoma	65	157,526	66,050	
Central N.Y.	60	92,492	63,700	
Metro D.C.	60	845,301	176,900	
Virginia	60	188,857	80,000	
Colo-Wyo.	52	362,621	174,240	Limit of ear-
Albany	40	175,975	130,940	marked funds
Puerto Rico	40	122,541	92,160	
Susquehanna	33	254,901	139,500	
Lakes Area	30	602,500	45,000	Discretionary
Wash/Alaska	21	361,167	75,000	Funding
Tenn Mid-So.	20	420,401	138,500	
		(\$12,584,242)	\$4,730,860	

<u>Disapproved</u>	
Bi-State	164,442
Connecticut	328,183
Florida	115,700
Illinois	449,000
Louisiana	335,528
Maine	74,346
Maryland	351,759
Missouri	693,362
Nassau-Suffolk	332,190
New Jersey	200,000
N.Y. Metro	227,829
No. New Eng.	10,000

1/ NOTE: Rank Scores relate to the modified program, and not to the original request.

DEPARTMENT OF HEALTH EDUCATION AND WELFARE
PUBLIC HEALTH SERVICE
HEALTH RESOURCES ADMINISTRATION
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Arthritis Ad Hoc Review Committee

Minutes of Meeting May 23, 24, and 25, 1974 1/ 2/
Parklawn Building, 5600 Fishers Lane
Rockville, Maryland 20852

OPEN SESSION

The Committee convened at 9:35 a.m., Thursday, May 23, to conduct technical review and to recommend action on pilot arthritis grant applications received from 43 Regional Medical Programs.

The basis of these grants is an appropriation earmark of \$4,500,000 in the 1974 appropriation for Regional Medical Programs for planning and development of pilot arthritis centers. With an Administration reserve of five percent, \$4,275,000 is available for support of this one-year program.

The total amount requested by the 43 applicants was \$15,865,000. The Committee made recommendations for approval of up to 31 of the programs with modified budgets totalling approximately \$4,600,000.

Dr. Herbert Pahl described the purpose of the Committee and charged it to consider the following major issues in its review:

- a. The establishment of a cohesive arthritis program, insofar as possible, rather than a series of projects.
- b. The essential elements of a one-year pilot arthritis program.
- c. The appropriate, respective roles of activities in areas with sophisticated arthritis capabilities, and those with minimal, or dispersed capabilities.

1/ Meetings are conducted in accordance with the Federal Advisory Committee Act. Proceedings of the closed portions of meetings, and materials submitted for discussion during such closed portions, are restricted unless cleared by the Office of the Administrator, HRA.

2/ For the record, it is noted that members absent themselves from the meeting when the Council is discussing applications: (a) from their respective institutions, or (b) in which a conflict of interest might occur. This procedure does not, of course, apply to en bloc actions--only when the application is under individual discussion

- d. Pilot program character with respect to centralization of effort, and opportunities to stimulate creative actions.
- e. The realistic scope of one-year program outcomes.
- f. The appropriate role of local Arthritis Chapters.
- g. Feasibility of proposals in the present state of the art.
- h. The desirability of giving additional weight to selected program elements, such as outreach, response to special population needs, and patient-focused rather than general public-focused program approaches.

Mr. Matthew Spear reviewed the background and development of the RMP initiative in arthritis. Miss Marjorie Morrill described how staff review was performed. Mr. Kenneth Baum provided an overview of common characteristics noted in the applications by staff reviewers. Applications for pilot arthritis grant funds included the following:

- 1. An inpatient or other central facility.
- 2. Satellite clinics, or some other kind of satellite or outreach unit.
- 3. A patient education component usually sponsored by the local chapter of the Arthritis Foundation.
- 4. A public education component, also sponsored by the local chapter.
- 5. Some applications proposed special children's facilities, or Lupus clinics.
- 6. Many applications omitted essential elements requested in the Arthritis Guidelines, in most cases, it is presumed, because of time constraints (e.g., justification of need, adequate evaluation, assurance of future funding).
- 7. Assertions that specific agents would assume responsibility for continuation of program elements were in no case accompanied by commitment letters which specifically pledged followup support.
- 8. Many applications contain requests for significant hardware acquisitions, including vehicles, laboratory devices and supplies, film and tape production and projection equipment.
- 9. Some applications contain clear, or implied elements of research, patient care reimbursement and professional fellowships and stipends.

Members of the Committee:

Chairman: Roger D. Mason, M.D.

Phyllis C. Annett, RN
Joseph P. Bailey, M.D.
William F. Donaldson, M.D.
Ephraim P. Engleman, M.D.
Henry L. Feffer, M.D.
Alicia Hastings, M.D.
John E. Kralewski, Ph.D.

Carroll B. Larson, M.D.
Frank R. Schmid, M.D.
Lawrence E. Shulman, M.D.
Frances B. Silverstein, (OTR)
Honora Wilson (SW)
Patricia Yarborough (PT)
Ex Officio: John Gramlich, M.D.

Others who attended the Review Meeting: (Names of attending DRMP staff are appended at the end of this document.)

Joan Fredericks NIAMDD-NIH
Bernice C. Harper, Div. of Long Term Care, BHRD
Frances Howard, National Library of Medicine
Ann Moldenhauer, HRA-OA-CMB
Muriel Shurr, Administration on Aging, DHEW
Irene D. Skinner, HRA-OA-CMB
Dr. J. Paul Thomas, Rehabilitation Services Administration, DHEW

Remarks by members of the Public were called for by Dr. Herbert Pahl. There were no comments by guests, and the Open Session was adjourned.

CLOSED SESSION

The Committee reviewed the 43 arthritis grant applications received, and agreed to priorities which would govern its recommendations. These were expressed in Resolutions and Guides voted by the Committee. The Committee expressly recognized that constraints placed on approvable pilot arthritis programs resulted in recommended disapproval of meritorious programs and activities, but which in the Committee's perspectives of program funding and time constraints, could not be undertaken effectively at this time. The Committee also agreed that its rules should not be completely rigid, and that it would recommend approval of otherwise excluded activities in selected, outstanding areas.

The Resolutions and Guides by the Committee are:

1. OUTREACH

Resolution: The major thrust of approved pilot arthritis programs shall be outreach.

Background: The Committee noted examples of requests for personnel, equipment, and other support for centers which appeared to represent an "overwhelming emphasis on the further development of an on-going

center." The Committee characterized this as "inreach." It was recognized that some support of centers is in order to conduct an outreach program. The center is often the source of reaching out, and upgrading of center resources to the degree necessary to initiate and conduct outreach is appropriate. The main thrust, however, should be the improvement of patient access to the health system, and the respective levels of care which it can provide. Facilitation of patient access and entry into the system should be emphasized. The intended thrust of the pilot arthritis program cannot be fulfilled if centers only keep bringing patients into the centers. While much should be expected of the larger, established programs, equal or greater needs and lessons are present in lesser developed areas.

II. DATA COLLECTION, AND AUTOMATED REGISTRIES AND DATA BANKS

Resolution: Separate arthritis data banks and registries should not be funded. Program statistics should conform to American Rheumatism Association (ARA) standards as these are developed.

Background: While it is recognized that specific data is required to plan, conduct, and evaluate pilot arthritis programs, the Committee was opposed to the expenditure of relatively large sums for a variety of data gathering and analysis activities, especially those proposed to be automated at many sites, and in different ways. It was noted that the ARA is conducting a study to develop standardized nomenclature and reporting, and these will be published. The support of automated data programs with the limited pilot arthritis funds appears to be premature, and unduly costly in view of the uniform approach to these needs which is being developed. The Committee felt that State Health Agencies would be more appropriately responsible for morbidity and prevalence data. There is pending Federal legislation which, if enacted, would more adequately address arthritis data needs.

III. FILM/TAPE DEVELOPMENT, AND PRODUCTION FOR PUBLIC AND PATIENT EDUCATION, AND OTHER INFORMATION PURPOSES

Resolution: Those portions of arthritis program applications which request support for the purchase of hardware for film and tape production should not be funded. The Committee would consent to the support of software costs if the program is otherwise approvable. The widespread development of such materials is not considered wise when superior products can be obtained through qualified sources. The Committee recommends that DRMP and the concerned RMP's cooperate to provide coordinated identification and procurement from central, qualified sources of widely needed film and video tape materials.

Background: While the Committee members were personally aware of the capabilities of films and cassettes for patient and other educational activities, it was not considered wise to support the volume and diversity of requests made for these purposes. The needs for such materials

is Nation-wide, and considerable expertise is required to efficiently produce high quality materials. The high cost reflected in the applications does not appear to be a productive way to employ the limited RMP funds. Previous RMP experience in this area has demonstrated that extraordinary administrative problems are encountered in obtaining first-rate products, even in facilities with sophisticated equipment and expertise. There are a number of institutions which operate high quality audio-visual facilities where equipment presently exists (Michigan was noted). It was proposed that the DRMP might cooperate through concerned RMP's to produce selected video tapes, on subject matter widely sought, through one or two experienced centers.

IV. PUBLIC EDUCATION (and fund raising)

Resolution: Activities geared solely to public education will not be supported.

Background: A number of the arthritis grant applications requested support for audio-visual equipment, vehicles, printing, publications, and items related to mailing, etc, for purposes of public education. The Committee deliberated on the distinctions between patient and family education, and professional and para-professional training which it viewed as meritorious and appropriate in the pilot program, and public education. The Committee determined that public education was not an appropriate use of the limited RMP arthritis funds. Such activities appear to be more appropriate for support by Chapters of the Arthritis Foundation, local departments of health, and medical societies. The Committee drew a distinction between undesirable public education, and other desirable types of education by noting the use of vans and other equipment used in British Columbia to provide services to patients, and to extend specific training and education to patients, their families, and local medical and health personnel about arthritis disease treatment. Another example is the dissemination of information about diagnosis and treatment of gout, an eminently treatable disease for which appropriate diagnosis and treatment is not always made available outside of centers. Such activities are appropriate elements of the pilot arthritis grant program.

Specific note was taken of requests for support of overt, or implied fund-raising activities. Use of Federal funds for this purpose is prohibited.

V. EQUIPMENT (including vehicles)

Guide: In view of the one-year availability of the RMP arthritis funds, lease or rental of expensive items of equipment should be seriously investigated before commitments are made to purchase.

Background: Activities without firm continuation support may unnecessarily commit limited funds to equipment which cannot be effectively utilized when program support ends.

VI. RESIDENCIES AND FELLOWSHIPS

Guide: The Committee emphasized compliance with DHEW policies with respect to professional training and education.

Background: Various applications included requests for support of residencies, fellowships, and other education activities which cannot be supported under RMP policies.

RMP's which did not apply for pilot arthritis program support, and which were not considered by the Committee were:

Indiana	Oregon
Memphis	Rochester
Mountain States	South Carolina
Nebraska	South Dakota
Northlands	West Virginia

The Committee individually reviewed and assessed the applications from the remaining 43 RMP's, and ranking, and ranking scores of applications recommended for approval were established by the Committee on the basis of modified program recommended by the Committee.

The Committee expressed interest and concern about effective arthritis program coordination and outcome. The following alternative actions were recommended for consideration by the DRMP, and the Bureau of Health Services Development.

A. Program Communication

1. The development and experiences of innovative activities conducted under the pilot arthritis program should be widely publicized.
2. A periodic newsletter, or similar communication about developments in the supported programs should be supported by BHRD. This would increase shared experiences, and reduce duplication of effort.

B. Program Development

1. Programs should be required to make quarterly reports.
2. Funded programs should proceed to acquire needed personnel, and to refine program priorities, methods and objectives in the context of final recommendations. At the end of 3 months, programs should be able to report that they are underway on clearly defined arthritis programs.
3. At the end of 6 months, funded programs should have all personnel and organization in hand, and be operational.

C. Program Evaluation

There should be a conference in 6 months, or so, at which the agency, and/or the Committee looks at what is going on among funded programs.

D. Disposition of Committee Recommendations

DRMP should advise the members of the Committee about National Advisory Council actions on the pilot arthritis program, and the final disposition of the earmarked funds.

Committee members stated, and reiterated their concern about funding for arthritis (from the Transcript) "...the efforts of this Committee have been exemplary as far as acting to the best interests and adhering to the guidelines proposed... we consider this a very meager effort toward a tremendous problem, and it in no way reaches a point of beginning to provide a solution of any definitive kind, and that additional funding to include many of the projects that were rejected, as well as a multitude of other projects which should have been submitted that were not submitted because of the guidelines provided by legislation should be considered when such monies become available."

The Committee adjourned at 1:35 p.m., Saturday, May 25, 1974.

DRMP Staff Members present at Meeting

Dr Pahl
Mr. Chambliss
Matt Spear
Kenneth Baum
Sylvia Berman
Virginia Dunleavy
Rita Fox
Gerald Gardell
Reynetta Hackley
Ethel Hawkins
Peggy Henson
Gloria Hicks
Bea Kauffman
Marian Leach

Walter C. Levi
Marjorie Morrill
Joe Ott
Mike Posta
Abraham Ringel
Morton Robins
Mildred Roelle
Jerry Stolov
Calvin Sullivan
Gerald Teets
Margaret Welsh
Joyce Wilkinson
Lee Van Winkle
Dick Russell