



E000496

NOTE.—DO NOT USE THIS ROUTE SLIP TO
SHOW FORMAL CLEARANCES OR APPROVALS

DATE

Oct 9, 1974

TO:

AGENCY BLDG. ROOM

~~DR. PAHL~~

~~MR. GARDELL~~

Draft of proposal on national arthritis
conference requested by Dr. Margulies at
meeting with Mr. Gardell, and Mr. Spear

- APPROVAL REVIEW PER CONVERSATION
 SIGNATURE NOTE AND SEE ME AS REQUESTED
 COMMENT NOTE AND RETURN NECESSARY ACTION
 FOR YOUR INFORMATION
 PREPARE REPLY FOR SIGNATURE OF _____

REMARKS:

last Monday.

(Fold here for return)

To

Matt Spear

From

PHONE

BUILDING

ROOM

TO :

FROM: Acting Director, Division of
Regional Medical Programs, BHRD

SUBJECT : Request for assistance in providing followup activities for the DRMP
pilot arthritis program

We would appreciate guidance and assistance on appropriate followup activities which should be carried out in connection with 29 funded Regional Medical Program (RMP) pilot arthritis programs. In its recommendations to the June meeting of the National Advisory Council, the Arthritis Ad Hoc Review Committee urged that the funded programs be provided overall coordination to produce a national program perspective. In this regard, the Committee also recommended that program reporting be established, along with mechanisms for information exchanges, and overall program evaluation. All of the Committee's recommendations were ratified by the Council.

The Division of Regional Medical Programs (DRMP) is constrained with regard to alternative initiatives for followup action by virtue of the order of the Court requiring that all of our funds be allocated to the RMP's. This has been done, and we are without funds to carry out more than minimal staff activities. The timing and circumstances of the grant application and award processes deterred the establishment of program coordination and evaluation capabilities outside of the individual RMP's. Thus, we are confronted with a \$4.5 million categorical grant program in which activities are dispersed, and without mechanisms for unified order, and evaluation.

ALTERNATIVES

Practical alternatives for followup activities appear to be the following:

1. Convene a national conference of representatives of the funded programs and other concerned institutions. The purpose of the conference would be to: a) identify mutual needs of the programs; b) specify the manner and scope of response to these needs; c) clarify the terminal role of DRMP in connection with the grants; and d) elicit program coordination and evaluation roles from among program participants, including organizations of the National Association of Regional Coordinators, and the Arthritis Foundation.
2. Establish central program reporting and evaluation procedures. These would be developed in BHRD, and administered directly, or through a contract.
3. Do nothing; i.e., indicate lack of interest in categorical program participation, and require terminal reporting during RMP phase-out.

RECOMMENDATION

We recommend that a national conference (No. 1, above) of funded program leaders be convened at the earliest feasible date. We conceive of the conference as a two, or three day workshop which, in addition to the objectives indicated above, would strengthen the involvement of the concerned professional groups, and stimulate quality program impetus and post-grant alternatives. The diminished interest of DRMP as the sponsoring Federal agency would be offset by the assumption of continuity

responsibility by the "arthritis industry", to the degree in which it is willing to respond. The persuasive impact of peer professional involvement is considered^a necessary offset to waning interest and effort as funding termination approaches. Indeed, such an effect will be critical in the face of stated Federal ~~dis~~^{withdrawal.}interest.

BACKGROUND

In communications with the RMP's with funded pilot arthritis programs, we have solicited their comments concerning program coordination and evaluation. To date, 21 of the 29 funded Regions have responded. The following suggestions overlap, as a variety of actions ~~was~~ were proposed by most respondents.

- A. 14 Regions desire a conference in some context. These responses included the following:
 - 6 urge an early conference
 - 4 suggest a conference soon after program startup
 - 3 suggest a 1-day "show and tell" session, only
 - 4 suggest two, or three periodic conferences
- B. Some Regions indicated various desirable program outcomes, but did not specify implementing procedure. Others urged RMP meetings in addition to the above, involving DRMP leadership, and site visits.
- C. All respondents expressed the need for information exchange, and some urged that a process of mutual assistance be established.
- D. Several Regions proposed program reporting formats, and procedures.

We believe that the proposed conference should be a one-time convention of all involved organizations and groups. Since any continuing activities

approved at the conference will be dependent upon voluntary execution, a maximum number of those who will be asked to report, or collaborate should be present. It appears that this should be an average of three people from each of the 29 RMP's. It would be desirable for all Project Directors to participate.

We have developed a breakdown of grant distribution, and program components in Exhibit A. We estimate that a total of 93 participants would include 29 RMP representatives, and 64 Project Directors. A total of 139 participants would include representatives from 44 additional institutions which are the reported sites of ^{significant} ~~major~~ activities.

To augment the declining Federal interest in categorical program involvement, we propose that DRMP participation in the conference be primarily that of Convener, with substantive agenda content to be developed and executed primarily by arthritis program participants. To effect this approach, the agenda would be developed by a small representative group, and Chair assignments made to other-than-DRMP participants. A schematic agenda is presented in Exhibit B.

ESTIMATED COSTS

The financial constraints presently experienced by DRMP are ^{paralleled} ~~equalled~~ in a number of RMPs and other ~~program~~ participating institutions. For this reason, and to underscore joint interest in launching effective continuing arthritis activities, we propose that:

- a. the cost of minimal conference participation be jointly underwritten by DRMP, the Arthritis Foundation, and the participating RMP's.

- b. the participation of other involved individuals be permitted at their cost.
- c. the conference be held at a mid-continent location to equalize travel costs, and to take advantage of generally lower charges at southern locations (e.g., Kansas City; Oklahoma City; Dallas; Jackson, Mississippi).
- d. the conference be scheduled for no more than three days.
- e. guaranteed support for participants needing subsidization be limited to a stated maximum.

Estimated costs of subsidization:

Per diem \$25 X 3 days	\$ 75
Other 5 X 3	15
Travel (air tourist)	<u>200</u>
Estimated cost per person	\$ 290
\$290 per person X 93 participants	\$26,970
Audio-visual, and contingencies	<u>3,030</u>
Estimated sponsor cost	\$30,000

Proposed support:

Arthritis Foundation	10,000
RMP's	10,000
DRMP	10,000

(AF, and DRMP staff costs are additional)

FF For your information, summary information about the funded pilot arthritis program is contained in Exhibits C-1, and C-2.

We will appreciate your comments and assistance in identifying appropriate DRMP support. We have discussed these estimates with an official of the Arthritis Foundation, and received informal commitment of financial support.

Enclosures

Pilot Arthritis Program

Geographic Comparison of Grants

Basis of geographic distribution:

East-West division is the Mississippi River

North-South division is a line beginning on the Mason-Dixon Line, extending down the Ohio River, and extending west from the confluence of the Ohio and Mississippi Rivers. California is divided equally between North, and South.

A. <u>Financing:</u>	<u>North</u>	<u>South</u>	<u>Total</u>
East	\$1,059,000	\$1,232,000	\$2,291,000
West	1,018,000	1,203,000	2,221,000
Totals:	<u>2,077,000</u>	<u>2,435,000</u>	<u>4,512,000</u>

B. Participating Regional Medical Programs:

East	7.0	9.0	16.0
West	6.5	6.5	13.0
Totals:	<u>13.5</u>	<u>15.5</u>	<u>29.0</u>

C. Head count of 29 RMP's, and recorded components (Max figure includes other participating institutions; e.g., Alabama Min includes 1 RMP representative, and 1 representative of the recorded Component; the Max number includes these 2, plus the 3 participating medical schools)

	<u>Min</u>	<u>Max</u>	<u>Min</u>	<u>Max</u>	<u>Min</u>	<u>Max</u>
East	20	36	25	34	45	70
West	24	35	24	34	48	69
Totals:	<u>44</u>	<u>71</u>	<u>49</u>	<u>68</u>	<u>93</u>	<u>139</u>

Pilot Arthritis Program

Schematic Agenda for Proposed Conference

First Day

Registration
Opening Ceremonies, Introductions
Conference Charge to participants
Designation of Workshops, and participants
Overview of salient issues
 Program reporting needs
 Development of potential papers
 Regional/Sectional opportunities for
 program enhancement
 Continuity funding needs, and opportunities
 Program start up and operating problems
 Information clearinghouse, and exchange needs

Second Day

Workshops
 Program reporting needs and methods
 Program evaluation needs and methods
 Program professional exchange subjects and methods
 Funding alternatives, and how to prepare for them
 Mutual assistance needs, and methods
 Functional assignment alternatives

Third Day

Presentation, discussion, and voting on proposals
Assignment of tasks, and schedule of activities
Reaffirmation of responsibilities
Adjourn

SUMMARY DESCRIPTION OF THE NATIONAL PILOT ARTHRITIS PROGRAM
TO BE CARRIED OUT THROUGH REGIONAL MEDICAL PROGRAMS

A national pilot arthritis program has been initiated in 29 Regional Medical Programs through special grants and program approvals. These grants were made possible by a Congressional earmark of pilot arthritis funds in the 1974 RMP appropriation. It is anticipated that approximately \$4,500,000 will be expended this year for the special pilot arthritis program.

The grant applications, received from 43 RMP's, were reviewed and assessed by the Arthritis Ad Hoc Review Committee, comprised of arthritis specialists from across the country, and the National Advisory Council on Regional Medical Programs. Reviewers formulated an arthritis grant review perspective to establish a uniform basis on which to analyze the applications under highly competitive circumstances resulting from total requests amounting to four times the available funds. The review perspective (or guides) defined program emphasis which, in addition to professional judgements of merit and achievability resulting from the review, lent increased cohesiveness to the overall approved pilot arthritis thrust.

The emphasis of the approved pilot program is the extension of present knowledge in arthritis diagnosis, treatment, and care, through coordinated services which demonstrate improved patient access to care, and extension of professional services through expanded utilization of professional and paraprofessional personnel, and existing community resources. Arthritis clinics will be established in medical centers, community hospitals, and other community health facilities. Educational programs in hospitals, and through visiting multi-disciplinary teams, will increase the arthritis-handling capabilities of hospitals and private physicians, and will equip larger numbers of medical and health personnel to support services in hospitals, clinics, and home care settings. Increased patient self-care will be demonstrated through the development of patient/family training activities. Seminars and workshops will be conducted at many sites for improved utilization of community resources for arthritis services, including home care guidance and surveillance. Existing health department personnel and facilities, and health groups such as the Visiting Nurse Association, local councils on aging, and operating community health worker training programs, are cooperating in demonstrations of improved arthritis health care delivery.

Several modest studies to develop criteria for quality care through provider performance standards are being conducted. An industry survey is planned in one Region, and an employee/employer education program will be developed in concert with better organized occupational health services. A number of programs are focusing on the problems of low income rural groups, and others are developing demonstrations of care delivery to economically disadvantaged inner city residents. Pediatric arthritis services will be developed in a variety of settings, and one program is demonstrating improved services to a geriatric population. Localities which presently have little, or no rheumatological resources are being supported in the initiation or expansion of new medical institution teaching capabilities. Across the country, Chapters of the Arthritis Foundation are providing program coordination, dissemination of publications, and increased numbers of volunteer workers in support of services and increased patient referrals to local services and resources.

The constraints imposed by one-year limited funds were keenly appreciated by the review bodies. It was recognized that while much valuable work could be accomplished with the earmarked funds, many meritorious activities could not be approved under the limited, one-year pilot character of this program. In this respect, the Arthritis Ad Hoc Review Committee noted, "...we consider this a very meager effort toward a tremendous problems, and it in no way reaches a point of beginning to provide a solution of any definitive kind..."

DIVISION OF REGIONAL MEDICAL PROGRAMS
BUREAU OF HEALTH RESOURCES DEVELOPMENT

The following capsule statements of arthritis program content are provided from the original applications, following Committee, and Council Review. A number of program changes have been effected, and are reflected where such changes have been reported to DRMP. The specifics of individual programs should be obtained from the RMP, or the principle investigators when more complete information is desired.

<u>RMP</u>	<u>Arthritis Program Synopsis</u>
<u>Alabama</u>	University of Alabama, Birmingham, will establish new arthritis clinics at Huntsville, Tuscaloosa, and Mobile. UAB will carry out periodic demonstration-teaching clinics at these sites for clinic staffs, local physicians, and PH Nurses.
<u>Albany</u>	Albany Medical College will establish two arthritis clinics with local staffing to serve rural populations.
<u>Arizona</u>	Arizona Arthritis Foundation, with a variety of University and other medical and health organizations, will develop a network of diagnostic, treatment, and rehabilitation services in the southern 6 counties surrounding Tucson. Multidisciplinary consulting teams, and local coordinating committees will be formed.
<u>Arkansas</u>	Arkansas Arthritis Foundation will coordinate the UA Medical Center, Little Rock VA Hospital, Leo N. Levi Nat'l Arthritis Hospital in the establishment of 6 locally staffed clinics in outlying population centers. An active education program will be provided.
<u>California</u>	CCRMP will coordinate service development and outreach activities at 8 centers; UC, Davis (JRA clinic); UC San Francisco; USC; UC San Diego; St Mary's Hospital, San Francisco; Orange County Medical Center; Loma Linda University; and Scripps Clinic and Research Foundation, El Centro. CCRMP, itself, may compile demographic information at one or two sites toward developing criteria of care.

RMP

Arthritis Program Synopsis

Central New York

Central NY Arthritis Foundation will coordinate activities of Upstate Medical Center, and others, to develop referral, diagnosis, and treatment services in outlying areas, especially northern and eastern rural areas of the Region.

Colorado-Wyoming

Rocky Mountain Arthritis Foundation will coordinate development and expansion of referral, diagnosis, treatment, rehabilitation, and training services at UC Med. Center, General Rose Hospital, Gottsche Rehabilitation Hospital, and St. Joseph's Hospital. Up to 8 new, outlying diagnostic and teaching clinics will be established, and visiting multidisciplinary teams will be formed.

Georgia

GRMP will coordinate activities based from Emory University, and Georgia Medical College to establish model arthritis programs in defined areas of the Region. Service networks will be developed, training will be expanded, and standards for diagnosis, treatment, and rehabilitation will be developed.

Greater Delaware Valley

GDV/RMP will coordinate activities in 6 institutions: Univ. Pa., Hahnman Medical School; Childrens Seashore House; Thomas Jefferson Univ., Albert Einstein Med. Center; and Temple Univ. Health Sciences Center. Diagnosis, treatment, and rehabilitation will be upgraded at a number of outlying sites. Professional education and training will be expanded. Pediatric services will be improved at a number of sites.

Hawaii

University of Hawaii will establish the (ATETCP) Arthritis Treatment, Education and Training Center of the Pacific, comprised of multidisciplinary staff. Extensive outreach services are planned in the Pacific basin, including technician, and patient/family training.

Intermountain

Univ. Utah will develop a number of primary and secondary care facilities in the Region. Multidisciplinary services will be developed as well as a home and midway care program. Education will be provided at U.U., especially focussed on development of primary and secondary care providers.

Iowa

Univ. of Iowa will establish clinics at Des Moines and Muscatine. Multidisciplinary teams will be established at each site, and professional education will be provided.

RMP

Arthritis Program Synopsis

Kansas

Kansas Univ. and the VA Hospital at Kansas City will collaborate in establishment of a referral, diagnosis, treatment, and rehabilitation system based on professional/patient information and education centers to be established at Kansas City, Topeka, Salina, and Wichita, under local sponsorship.

Metropolitan D.C.

Freedmen's Hospital, and Washington Hospital Center will establish inner city referral, diagnosis, treatment, rehabilitation and training programs.

Michigan

Univ. of Michigan will establish a program specifically dealing with needs and problems of geriatric patients (age +55) in a selected area. Special emphasis will be placed on patients who can be made ready, or who are recently released from institutional care. Professional and patient education and training will be provided.

Mississippi

Univ. of Miss. Medical Center, and the Methodist Rehabilitation Center will establish up to 4 clinics in outlying sections of the Region with physicians trained and cooperating closely with central resources in Jackson. Training will be provided for physician and allied health personnel, and for patients. A nurses handbook in arthritis care may result from a proposed RN preceptor program.

New Mexico

NMRMP will coordinate activities of the Univ. N.M., N.M. Arthritis Foundation, and others in establishing 2 outlying clinics in selected areas, one of which may incorporate pediatric services. Multidisciplinary teams will be formed, and local community coordinating committees will be established. Professional, allied health, and patient/family training will be provided.

North Carolina

N.C. Arthritis Foundation will coordinate a variety of activities. It will also organize referral services, provide literature, and conduct a detection program at Burlington Industries incorporating the development of services, and a model employer/employee education program. The Asheville Orthopaedic Hospital and Rehabilitation Center will train allied health personnel as physician assistants, including drug toxicity monitoring. Univ. NC, Chapel Hill, will improve its clinical operations, and provide a multidisciplinary team to assist the development of outlying model clinics. Duke Univ. will establish outlying clinics, and provide

RMP

Arthritis Program Synopsis

professional training. Bowman Gray School of Medicine will establish multidisciplinary teams to improve and expand services at several existing community clinics.

North Dakota

N.D. Medical Research Foundation will coordinate the establishment by the Dakota Medical Foundation of 2 pilot centers to develop service delivery systems in designated areas of the Region. Multidisciplinary teams and itinerant services will be developed. Medical planning groups will assist coordination, supervise program, and relate activities with AHEC's for coordinated training.

Ohio Valley

Louisville General Hospital, primary center for low income and minority city residents, will expand its services to coordinate a care delivery system in cooperation with Community Hospital, and the VA Hospital. Overall supervision will emanate from the U.L. School of Medicine, Section on Rheumatic Disease. Combined multidisciplinary medical conferences will be held. Emphasis will be placed on home care services with active participation of the VNA, the Arthritis Foundation, and other community agencies. Increased professional and patient/family education will be provided.

Oklahoma

O.U. Health Sciences Center will enlarge clinics sponsored by the OU., and VA Hospital, to improve available services. A pilot outreach program will be organized in cooperation with the Ada Regional Health Development Area Program, as a demonstration in improved rural health services.

Puerto Rico

P.R. School of Medicine will develop a model clinic at the Medical Center, and at least one clinic at an outlying community for improved referral, diagnosis, treatment, and rehabilitation services. Professional, allied health, and patient/family education will be provided.

Tennessee Mid-South

Vanderbilt Univ., with cooperation of the VA Hospital, and the Nashville Metropolitan General Hospital will establish a center at V.U. One or 2 outlying clinics may be established related to improved adult and/or pediatric services.

RMP

Arthritis Program Synopsis

Texas

TRMP, Inc., will coordinate a variety of activities at 5 medical schools, and cooperating Texas Arthritis Foundations. UT Medical Branch, Galveston, will develop a model minimal care unit for serious, chronic arthritis, to simulate the home environment while patients undergo PT/OT therapy, and related services. All major medical schools, large clinics, medical societies and the Arthritis Chapters will cooperatively establish a State-wide education program. Conferences and clinic's for professional and patient audiences will be scheduled at many communities. A series of regional workshops for practicing allied health personnel will be conducted at several major institutions. Postgraduate refresher physician courses will be presented at several institutions; also, 75 Texas, and 13 other hospitals will have access to conference telephone seminars from UT, San Antonio. A number of existing clinics will be expanded and additional home service and other outreach activities may be generated.

Tri-State

T-S RMP will coordinate activities of several institutions. Boston City Hospital will develop a multidisciplinary team and expanded services for outreach to inner city residents. Emphasis is on development of allied health personnel and physician assistants. Tufts New England Medical Center will develop community clinics at a number of outlying Massachusetts, and Maine locations, designed to facilitate multidisciplinary diagnosis and treatment services. Professional and allied health education will be developed in relation to the needs of the program.

Virginia

Virginia Arthritis Foundation in cooperation with MCV, and U.V. Hospital, will coordinate the establishment of a number of community satellite clinics, with emphasis on the southwestern area of the State, staffed by local physicians and allied health personnel. Multidisciplinary teams will provide training, and assist clinic development. Patient education will be developed.

Washington-Alaska

Western Washington Arthritis Foundation will operate an PT/OT training program at the Virginia Mason Medical Center for personnel from Washington, Alaska, Idaho, and Montana. Support for participants from Idaho, and Montana must be borne by their sponsors. Home therapy will be taught at WWCAF. Up to 40 therapists are expected to be trained under this program.

RMP

Arthritis Program Synopsis

Western Pennsylvania

St. Margaret Memorial Hospital and Schools of the Health Professions, University of Pittsburgh, will collaborate in establishing a network of centers in both inner city (Alleghany only), and up to 6 other western Pennsylvania communities, locally staffed. Multidisciplinary teams will help locate, organize, and provide periodic consultation to the centers. Physician and allied health training will be provided at up to 10 Regional facilities. In addition to disease phenomona, training will cover the roles of various community health resources; increased use of vocational assessment, rehabilitation, and counseling services will be promoted in all courses. A health resources directory will be developed.

Wisconsin

Wisconsin Arthritis Foundation will coordinate 3 pilot activities. A pilot patient/family education program will be conducted by the Sacred Heart Rehabilitation Hospital. A pilot, multi-hospital quality assurance of nursing care for selected patients (early RA, and total hip replacement) will be conducted by the Columbia Hospital. Professional health education will be fostered through visits of multi-disciplinary teams formed from the medical schools, and their major affiliated hospitals.