E000513

HEW REGIONAL OFFICE, ARTHRITIS FOUNDATION, AND OTHER SUGGESTIONS FOR

ARTHRITIS PROGRAM COORDINATION AND FOLLOWUP

ARTHRITIS FOUNDATION

I would like to make some additions to that correspondence. First, I believe we should have periodic meetings of all RMP Grant recipients during the funding year. These meetings should be working conferences where the number of participants would be restricted. The maximum number of individuals I would include would be two from each grantee institution, two representatives from the National Arthritis Foundation and about a half-dozen experts in the field of medical care and training evaluation, plus of course, appropriate RMP officials. I specifically emphasize the need for medical care experts since such individuals would be used as consultants to guide the conference in its program evaluation and assist in modifying efforts to achieve optimal programs. These individuals would also be important in keeping such a meeting from becoming sessions of "vested interest". I am thinking in terms of persons like Dr. Kerr White of Johns Hopkins University, Dr. Avedis Donavadan, Dr. Kurt Deuschle and other individuals with similar specialized backgrounds. Significant rheumatological expertise would be provided by a rheumatologist from each of the awardee institutions.

The objectives of these periodic meetings would be as follows:

1) The presentation of individual programs.

2) To note progress made.

3) To present problems encountered in the conduct of the programs.

4) To report on efforts made and success in obtaining monetary support beyond the funding year.

5) To establish evaluation guide-lines for the programs.

6) To standardize certain elements of the evaluation in order that data can be compared across programs.

7) To compile progress information to use in promoting to the public and to legislators the over-all impact of the programs.

The establishment of our evaluation guide-lines of programs (my #5) represents a difficult problem. I can foresee that it should be subdivided into #1: the evaluation of patient care programs or activities and #2: the evaluation of training programs. The specifically mentioned individuals above would be very important in establishing these guide-lines for evaluation. I would not at this point offer any specific recommendations because I think this could be more easily accomplished in an initial conference.

It would seem to me essential to store standardized information from each program in a central computer facility in order to accomplish overall evaluation impact of the programs.

To organize the work conference I believe would best be accomplished through the combined efforts of the RMP and the National Arthritis Foundation. Again I refer to my letter of June 7th (paragraph 4) regarding the basic format for these conferences.

NATIONAL INSTITUTE OF ARTHRITIS, METABOLISM, AND DIGESTIVE DISEASES

I appreciate your initiative manifested by the information forwarded to this Institute concerning Regional Medical Programs (RMP's) new effort to extend present knowledge in arthritis diagnosis, treatment, and care through coordinated services. From our point of view - and perhaps yours, too - the concurrent developments related to arthritis programs together with the existing programs should be balanced, integrated, and evaluated to achieve coordinated support which could exist as a continuum with basic research and care as the limits.

If RMP finds it desirable, consideration might be given to defining more clearly the interface between our respective efforts. Noteworthy in this endeavor would be the part played by the local chapters of the Arthritis Foundation that seek to support clinical centers and the pending arthritis legislation which would intensify NIAMDD's initiatives in this field. To this end it would be helpful to know who the people involved are that are associated with specific RMP awards to examine and compare them with our own training and center support in the same geographical areas. Further, the Arthritis Foundation's perspective on this development together with their own support programs could be obtained through direct Institute contacts. Finally, in addition to the specifics and principals involved in the 29 awards (perhaps the 14 unsuccessful applicants as well), it might be helpful to have the recommendation of RMP's Ad Hoc Arthritis Review Committee concerned with intercommunication, reporting, information exchange, and program evaluation.

DIVISION OF LONG-TERM CARE

1. Training curricula for physicians, nurses and allied health personnel, as well as patient education materials developed for use in these pilot demonstrations, be submitted to the Division of Long-Term Care for incorporation into its Media Center currently being developed. The Media Center will serve as a source of published material, audio-visual aids, training curricula, and research documents related to gerontology as well as to the health, environmental and psychosocial aspects of long term care. It will be for the use of contractors, students, researchers, and others concerned with this subject area.

2. Regional Conferences of project directors should be held in January and in June for exchange of information, including discussion and analysis of problems and progress. A summarized report of each Conference should be prepared and distributed to all project officers. Through this mechanism, all project directors could be apprized of significant activities, and could individually follow up if more complete information is needed. From information contained in these reports, a project

director in one region might feel that his experience could be of assistance to a project in another region, and he could then initiate communication with that project to offer valuable guidance.

3. Working subcommittees could be appointed to develop data reporting systems for a variety of subactivities such as patient services, fiscal data, and training programs.

FRANCIS SILVESTEIN, OTR (Member of former Arthritis Ad Hoc Review Committee)

Obtain and circulate thorough but brief factual descriptions of each pilot project for inter-project circulation
Follow at 3 month intervals with reports containing findings regarding successes, failures in original plans, and necessary changes as they evolve
Outlines or adgendas of each presentation, program, meeting, etc., which contributed toward the growth of the project
Outlines or copies of each presentation, program, meeting, written material, etc., which is used for educational purposes, including a description of the audience to which they are directed

In short, full circulation of a variety of abstracts from which the other projects can derive information or ask questions on matters of interest specific to their own work, in order to obtain material to be applied to it. With such a short period of time available for this work, the ability to bypass the learning and trial period is, I feel, vital.

VETERANS ADMINISTRATION

Dr. Rosenberg was recently reassigned to the position of Assistant Chief Medical Director for Policy and Planning (17). From the standpoint of the VA programs in Internal Medicine, I have reviewed the material which you have provided. I am very pleased to note the involvement of several VA hospitals in the arthritis program in conjunction with affiliated medical schools and related institutions. I do not, however, have any suggestions at this time for innovative methods for facilitation of program quality or ways to capture experiences of this program for further assessment, interpretation and promulgation.

HEW REGIONAL OFFICES

Region III - Philadelphia

I appreciate the opportunity to offer my comments on the National Arthritis Program to be carried out by the Regional Medical Programs in this region. However, I find it difficult to respond to your specific request given the information provided, except in very general terms. These projects may touch upon a number of HEW programs and objectives, particularly in the Public Health Service. The material I have received has been forwarded to the Regional Health Administrator for his information.

One of the most important programs in this regard is Comprehensive Health Planning, which has the mandate of determining local priorities of health programs. It is very important that the state and local planning agencies not only be involved in the development of federal programs and in the review of projects, but that they be kept informed of decisions which would affect the resources available to their communities.

I urge you to work with the Regional Health Planning Branch, PHS, in continuing the dialogue between the health planning agencies and the Regional Medical programs.

Region IV - Atlanta

In response to your request for comments on the pilot arthritis grant funds and the concern that the pilot centers may develop and effect a coordinated effort, I feel that our review of the summaries is for our information and to be utilized with our ongoing activities for proper program intercommunication.

Since this is one year limited funds, the application already written and approved by each RMP staff and advisory group, our comments would be "after the fact" and I feel that any effort by either your staff or mine to "assist in addressing those issues common to each center" would be futile.

The goal of this limited effort is commendable and we will share the background material and brief description of the RMP activities with our staff and States. It is important for the success of the program that cooperation between Regional Medical Programs and the official Public Health Agencies of each State be encouraged. The traditional role of Public Health Agencies has always been one of cooperating and providing information to support programs such as this.

Region VI - Dallas

It is highly desirable to maximize feedback and crossover of information between the programs as experience is gained in each, such that the experience of each can optimize program modifications in the others. Unfortunately, we are faced with severe constraints that will make participation by this office difficult, if not impossible.

Our first constraint is the lack of manpower to assist in the coordinative effort. Region VI has had no positions assigned to it for Regional Medical Programs since 1973. As you know, our PHS activities are utilizing Management by Objectives and we have already agreed to a specified program of work plans for Fiscal Year 1975. An effective coordinative effort for pilot arthritis programs would require considerable resources, resources already committed in the Fiscal Year 1975 Work Plan.

The second constraint shared by both of us is the one-year duration of these pilot programs. Evaluation of program activities, feedback to the grantee and subsequent modification of program activities would be most difficult in the time span available.

We recognize the value of coordination of grant programs at all levels. However, given the above constraints I do not know how our Regional Office can make an effective contribution to the pilot arthritis programs during the current fiscal year. Perhaps we can assist you if the activity continues into Fiscal Year 1976. If so, please include your request in Fiscal Year 1976 HRA Work Program Guidance in order that we may prepare our work program accordingly.

Region VIII - Denver

The following are suggested approaches you may wish to explore as ways to capture the experience of the pilot arthritis programs:

1. Establishment of a National Ad Hoc Task Force or National Arthritis Advisory Council -- to assess the pilot arthritis activities and make recommendations for direction of future efforts.

2. Health Service Administration -- to interpret the pilot arthritis activities in terms of program implications.

3. National Institute of Arthritis, Metabolism, Digestive Diseases -- to interpret the pilot arthritis activities in terms of research implications.

4. National Arthritis Foundation -- to promote program intercommunication and education of the public.

5. PHS Regional Offices -- with staff support the Regional Offices could foster the development of regional coordination.

6. Division of Regional Medical Programs -- to serve as a locus for the national arthritis initiative. This is based on the assumption that ongoing arthritis program activities in the DRMP will be absorbed by whatever health systems agency is to be created by the new legislation.

Region X - Seattle

One activity the Division of Regional Medical Programs could support is the development of an informational exchange among grantees to support a network activity for arthritis much like the endstage renal dialysis network activity. A second activity could be to support legislation such as that proposed by Senator Cranston to develop an approach like heart, cancer, and stroke, to plan and develop these networks. A third suggestion is that the Comprehensive Health Planning agencies be apprised of the needs in the arthritis area so they can consider this problem as a part of their activities.

Arthritis, like a number of other program categories, perhaps should be singled out as an area in which regional and national resources should be spent. The decision has not been made for arthritis to have resources committed to it on a continuing basis and maybe this one year of funding can develop activity within the states, and areas of the states, to encourage providers and associations interested in the arthritis program to think in terms of networks and levels of care so a continuing activity can be initiated at these levels.