

Will postgraduate training of established medical and paramedical personnel reach those physicians, scientists, and others who have the earliest opportunity to apply preventive measures against disability?

Will the experience of postgraduate education in related public health endeavors indicate whether postgraduate education can hasten the solution of public health problems that are presented by disability from arthritis?

Other related questions arise, such as:

When does the arthritic patient need the attention of the specialist—medical or paramedical—for the prevention of disability?

Is the current use of local hospital and other medical facilities, university medical or other research centers, and public health offices the best approach to the prevention of disability from arthritis?

Can restorative measures or ordinary domiciliary care be used to better advantage, or modified readily, for prevention of disability?

Would it be pertinent to know whether comprehensive public health surveys

could determine, accurately, the numbers of arthritic patients for whom medical or paramedical care (or both) is needed to prevent disability?

Where are such patients in relation to the availability of the skills they are thought to need?

How might patients be motivated to use available preventive measures?

What is the significance of the socioeconomic aspect of disability from arthritis on the patient, family, and community?

Certain of these and related questions are more particularly the province of other Workshops in this conference, namely, those that are concerned with public education and information, diagnostic and therapeutic facilities, long-term management, clinical investigation and the training for it, voluntary and public agency activities, and socioeconomic factors. Likewise, the questions that are pertinent to postgraduate education may not all be separable from their specific approaches. However, in so far as it is practical to do so, our attention will be directed, particularly, to solution of the problems of professional education, as it is related to prevention of disability from arthritis.

Hopefully, such attention might also contribute toward solution of those other aspects of the prevention of disability that are being considered in the other Workshops in this conference.

Workshop 5

Clinical Investigation and Training

John L. Decker, M.D., Chairman

“Clinical investigation” is, in the current language of the medical scientist, commonly interpreted as encompassing a wide field, from electron microscopy to the indications for synovectomy, from the structure of peptides to population studies, and

from the problems of membrane potentials to the psychologic impact of chronic invalidism. While recognizing and rejoicing in the breadth of this definition and in the fundamental role of the more basic approaches to generating new avenues of thought and investigation, the clinician, and with him, our society, is confronted, now, today, with the unfilled needs of the rheumatic disease patient. A part of the title of this conference, "prevention of disability," makes the point clearly. The way to prevent disability is to prevent or cure the disease. Despite some hopeful flickerings on the horizon, flickerings that need continued nourishment and hard work, these routes are not now open. Another way must be sought.

It is this effort—to address ourselves directly to the individual patient, to understand the framework in which his disease develops, to diagnose and classify his illness, to predict its outcome accurately and to manage it in such a way as to prevent disability—which constitutes "clinical investigation" in a more restricted form and is our subject, here.

There is no clear dividing line between "basic" and "clinical" investigation; and it is unwise to seek or to draw one, for

each flourishes best when enlightened by the other. The emphasis on the patient and on his problem that is expressed here is not meant to denigrate more fundamental studies, nor to imply that there is only one way to do things. Obviously, there are many avenues; but it is our present purpose to explore the possibilities and pitfalls of one, only.

Within the health professions, "arthritis" means inflammation of the joint. Thus, this conference has great breadth, in terms of specific diseases. In selecting a specific area or disease for work, many considerations, some appropriate and others distinctly inappropriate, assail this conference (and the investigator). The choice might be based upon quantity. Which disease is most common? Degenerative joint disease? Which disease causes the greatest economic loss and misery? Rheumatoid arthritis? The choice might be based on scientific considerations—that is, where the leads look best. Which disease seems more likely to be due to infection? Reiter's syndrome? Which disease permits study of the synovia before, during, and after induced inflammation? Gouty arthritis? The choice could be based upon its current "popularity rating"; no granting commit-

tee can entirely divest itself of medical fashion. In which disease do genetic factors seem most pertinent? Ankylosing spondylitis? Which disease is the prototype of "autoimmunity?" Systemic lupus erythematosus? Or perhaps the considerations should be more practical. What disease will be troubling the largest proportion of the next one hundred patients to be seen? Fibrositis?

In practical fact, all of these considerations, and more besides, enter into the choice. For our purposes, it is sufficient to recognize that choice is difficult and that it is foolish to restrict or to delimit, unduly, the area of concern. The diseases that cause crippling overlap in a myriad of fascinating ways, and the study of the exotic is no less (nor no more) to be preferred than the study of the common.

The prototype disease, and the major public health problem, is rheumatoid arthritis. While most of our thinking will be concerned with rheumatoid arthritis, lessons that are learned in other diseases will apply to rheumatoid arthritis; and, conversely, many of the conclusions that are reached will have validity beyond rheumatoid arthritis, alone.

This essay will cite a few approaches to

knowledge that can be applied to preventing disability from rheumatoid arthritis. It will discuss the difficulties which tend to hinder these investigations. And it will suggest means of eliminating some of these obstacles. The nature of the professional training that qualifies individuals for such work will be considered.

I. Problems for Clinical Investigation

The number of unanswered questions that are concerned with rheumatoid arthritis is unlimited. Much of the operating knowledge that is now in general use has not been "established," in the rigorous scientific sense of the word. Consequently, almost all of the thought and action patterns of today's clinician might be considered to be in need of reevaluation.

In practical fact, the last 20 or 30 years have provided a reasonable baseline of knowledge, both in the literature and in the abilities of physicians and others who have been privileged to observe the disease in large numbers of patients. A good example of this baseline knowledge exists in the criteria for the diagnosis of rheumatoid arthritis, which was first suggested in 1957 by a committee of the Rheumatism Section of the Arthritis Foundation. These

criteria continue to serve a most useful purpose; and they deserve the constant reappraisal that was suggested by the original committee and, recently, begun. Thus, there is need for clinical investigation of the foregone conclusions of the past, as well as of the new tools, ideas, and modalities of today.

Early identification of the disease continues to be a problem; but it should now be extended to efforts to identify susceptible individuals before overt onset of disease. What is the meaning of serum rheumatoid factor in healthy individuals? Studies of rheumatoid arthritis in populations, both at one point in time or with continuing reappraisal of a population sample, have proven to be useful, in terms of defining the magnitude of the problem and of permitting the drawing of conclusions as to its nature. For example, the low order of familial aggregation that is found in surveys of special populations raises important questions about the disease, which appears in certain families at a rate far beyond that expected.

The natural history of the disease deserves constant study, as do its relationships to other illnesses, such as chronic ulcerative colitis or psoriasis. The recently

changing views of the distinctions between rheumatoid arthritis and ankylosing spondylitis provide evidence that this type of nosological effort is still valid today. Indeed, there are cogent reasons to believe that "rheumatoid arthritis" is not one disease, but several. For example, are the monarticular, large joint disease of adolescence, the destructive, nodular disease of the metacarpophalangeal joints in young adults, and the chronic inflammatory synovitis of shoulder and knee of old age the same disease of the same cause?

More information is needed about such freely used terms as "active," "inactive," "suppressed," "burned-out," and "in remission." They have received careful attention in recent years, but one cannot escape the fact that the local destruction of a wrist, for example, seems, on occasion, to progress inexorably, while the systemic disease is regarded as inactive. Can distinctions be drawn and quantitation achieved between "local" and "systemic" activity? Would it be worthwhile to develop prognostic indices for individual joints?

The fundamental need to distinguish patterns, classes, and types of disease rests not in a desire to create more eponymic

syndromes, but, for our purposes, to achieve a more definitive prognosis. This is a prerequisite to properly planned therapeutic investigation, as well as to an enlightened treatment program for any one individual. This, too, has been done in the past, both retrospectively and prospectively. But new data handling methods, coupled with precise, prospective definition of the variables, should produce new insights.

The events that surround remissions and exacerbations of the disease deserve study. Such changes are regarded as spontaneous, but it seems likely that there are unrecognized contributing events, be they psychosocial, infectious, traumatic, or environmental.

The entire area of treatment, or management, lies open to clinical investigation. Only in recent years have properly controlled studies of corticosteroids, gold, and antimalarial therapy become available. Some attention has also been directed to non-medicinal approaches, such as long-term hospitalization, or immobilization, in reducing joint inflammation.

Among physical measures that are often recommended, few have been validated by exacting studies. Such matters as bed rest,

range of motion and muscle-building exercises, the role of heat in its various forms, and preventive exercises deserve analysis.

There has been much recent interest in local therapeutic measures. Both (intra-articular) injections and surgical approaches have been advised. No controlled studies are available. Early synovectomy—that is, before cartilage damage—cannot readily be advised nor accepted by the patient, unless it is established that it is not, in itself, a damaging procedure and that joint disintegration can be prevented. Reparative surgery has been in use longer, and its benefits are more evident, although, even here, it is essential to define results in terms of useful function, rather than in terms of pleasing cosmetics. Despite the many variables that are involved, appropriately designed studies, evaluated over an adequate period, should provide the needed definitive evidence on which to construct therapeutic plans.

II. Inhibitors of Clinical Investigation

The present paucity of studies of the type that have been described is readily accounted for: they are difficult to perform. In considering or conducting such studies, the investigator often finds himself

stopped by an insuperable problem or by a combination of problems. It is appropriate to examine some of them.

The nature of the disease, itself, is obviously the key factor. It is chronic, very different from patient to patient, given to abrupt, seemingly inexplicable changes in activity, and thoroughly intermingled with the emotional and physical nature of its human victims. There are no comparable animal models. These facts force the conclusion that appropriate studies require large numbers of patients and extended periods of study, measured in years and decades, rather than in weeks or months.

The investigator, then, must have qualities that are far from universal, such as infinite patience; the ability to design appropriate studies that are based on an exhaustive knowledge of the disease; a foresighted perception of what questions or problems will be of significance when his work comes into its final phases; the ability to inspire and to stimulate his associates; and the sustained and communicable concern for his patients that is the mark of the good physician. One of the inhibitors of clinical investigation in the rheumatic diseases is immediately clear: such paragons of virtue are rare, if not

altogether unknown!

A stable and reliable patient population of sufficient size is not always available. In many areas, this factor may hinge upon adequate transportation facilities. Many studies require a degree of patient understanding and cooperation that can rarely be attained in the average clinic population.

Patients who are able to pay a fee for services should be included; presumably, no charges would be made while they are "in" a study. There are major ethical factors that inhibit (perhaps properly) some work. Is it ever appropriate to perform sham surgery or to give a lactose placebo over years?

Inadequate cooperation between the various medical specialties is another potent inhibitor. Occasionally, this is based on long tradition or petty jealousies; more often, it is rooted in a failure to take the time to understand the ideas, methods, and motives of another discipline.

The expense of prolonged hospitalization, crucial to some work, has been an inhibitory factor where "free beds" are not available to the investigator. The high cost of this type of hospitalization within the institutions in which clinical research

is being done has made this form of support difficult to obtain.

An additional important problem is the pressures that are put on the physician who *does* have a few such beds at his command. The demands and the need for chronic hospitalization are so heavy and so pathetic that it requires a heart of stone to maintain the integrity of such a unit for investigational purposes, alone. The only reasonable solution is the provision of a chronic disease facility, with beds at a lower cost than those in the general hospital, but in *close geographic proximity* to the medical center. Such a facility is consonant with the rapidly increasing proportion of chronic to acute problems that is now being noted in medical practice, with the increasing mean age of the "average American," and with the overwhelming need for better training in chronic disease for all of the health professions.

To return to the inhibitors of clinical investigation, freedom, when it is denied the clinical investigator, is an inhibitor that deserves more deliberate mention. Creative work requires time, imagination, effort, and an environment that encourages opportunistic ventures into the unknown. The investigator can readily find himself

nailed to the rack of a protocol that was written years before, unable to exercise his originality and imagination. Worse than this, he can be so burdened by the multitude of administrative responsibilities that are sure to result from the problems that have already been cited that he lacks the spirit or mental energy to pursue even his protocol, much less anything new. His freedom must be preserved.

In the last analysis, monumental effort on the part of the investigator can overcome most of these problems. Then, the urgency and the pertinence of the hypothesis that is to be studied become of overriding importance. It is obvious that an hypothesis that involves basic attributes of the disease process is more compelling than an hypothesis that will require hundreds of man hours and scores of patients to determine whether Pill X or Procedure Y has an effect that is beyond that to be expected from chance, alone.

III. Encouragement of Clinical Investigation

Our discussions will center on possible means of encouraging clinical investigation. A major segment of the problem, which might be entitled "The Care and Feeding of the Clinical Investigator," is

considered next (IV). Other factors that apply include:

- a. Where should this type of investigational activity be done? Within a medical school? Within a research institute? Within the practice of medicine, either by individuals or in groups? What financial arrangements are appropriate for hospitalization for clinical investigation?
- b. Cooperative studies. Should all or any portion of this work be carried out with central direction to a number of operating units? How should these ventures be organized and by whom?
- c. The enthusiastic support of the local community, both lay and medical, can make a great difference. How can this be assured?
- d. The services that are required in any particular study—laboratory, physical medicine, transportation, follow up, etc.—will differ; but they must be available. Almost all will require consultative assistance in experimental design and statistical analysis. How can such facilities be made available?

IV. Training for Clinical Investigation

In the last analysis, the ideas that will build tomorrow must come from the mind of a man today. The research team, as a group, contributes to the environment of each individual on it; but an individual concerns us here. Any improvement or increase in clinical investigation has a single *sine qua non*—the investigator himself. As suggested above, he must be a man of many parts.

It is desirable that the creative individual be identified as early as possible and be introduced to the field in such a way that he will wish to enter it. Important consequences of this view are that training units for rheumatic disease should be widely dispersed in our educational system; that they should be in a position to recruit men to the field; and that the process of early identification is to be expected to bring many more into training than will actually perform adequately as independent clinical investigators.

The training will have to be flexible. The only requirement should be that the trainee must attack and master one area, no matter how limited, in depth. It seems unwise that all trainees be versed in a pre-

clinical discipline, although this would be the course for many. It is assumed that the trainee will be involved in clinical investigation and that the majority of his training will come in the one-to-one relationship with the preceptor, who is jointly involved in his problem.

All training units cannot (and should not) have competence in *all* disciplines. The trainee should be directed to the best possible position for the accomplishment of his purpose, be it a basic science unit, another rheumatic disease training unit, or a specialized institute or program.

Starting independent work represents the point of greatest attrition, perhaps rightly so. Appropriate support mechanisms should be available to permit the truly competent man to pursue his problem in a status beyond that of trainee. During this period, which might extend to three or four years, he should be free of heavy administrative or teaching responsibilities. He should complete the period ready to assume a permanent role as a clinical investigator.

He should be assisted and guided in finding a post that will permit the full utilization of his talents. As of today, this post is usually conceived of as an academic

appointment within a medical school. As more emphasis is placed on the investigational aspects of patient care, however, it seems likely that suitable posts will open up in hospitals, private clinics, and foundations; with proper direction and relationships, a suitable environment can readily be developed in such circumstances.

The mode of support for the clinical investigator is crucial. The rapidly recurring need to demonstrate "progress" to the granting agencies, both private and governmental, has tended to direct efforts toward limited and short-term goals. On the other hand, the difficulties of a *carte blanche* program of, for example, 15 years duration are obvious. Some intermediate mode may be necessary for people who work in the field of treatment of the rheumatic diseases.

Some of the unsolved, and perhaps unsolvable, problems of training investigators for work in rheumatic diseases include the following:

- a. Is all of medical school necessary to produce a specialized clinical investigator? There are reasons to believe that advancing age and the brainwashing of the average medical school curriculum smother originality. Should

there be "short cut" routes to clinical investigation? Might some subject areas be dropped and others fortified?

- b. Should training of clinical investigators be the responsibility of a few (less than ten) strong and especially organized training units?
- c. How can the trainee be encouraged to keep his breadth of vision wide while he is concentrating on a limited problem and using circumscribed modalities? Should he be exposed to a survey period during which he would study a wide range of techniques and their limitations?
- d. Would a regular pattern of rotation of trainees among several training units serve a useful purpose?
- e. Is a critical investigator born, or can the talent be developed? The ability to design clinical studies, to select properly matched controls, to analyze the many variables that are involved, and to appreciate what has and what has not been shown to be fact, seems to be rare. Are these talents "teachable?" If the answer is affirmative, should the teaching be by precept only, or can formal courses or programmed instruction be a major benefit?

Workshop 6

Voluntary and Public Agency Activities and Programs

William D. Robinson, M.D., Chairman

In spite of the growing recognition of the importance of the effect of rheumatic diseases on the health and economy of the community, there is little precise information available on the prevalence of these diseases in the general population. According to the United States National Health Survey of 1961-1963, rheumatic diseases caused a loss of 12 million man-days each year, with 13 million people in this country estimated to be affected. An estimate of the degree of crippling that was attributed to these diseases was also provided by this survey: 157,000 individuals were confined to their homes because of rheumatic diseases.

Another index of incapacitation is provided by the roles of applicants for disability benefits under Social Security.

During the period of this three-year survey, 30,000 arthritic applicants a year were unable to work for six months and were eligible for Social Security disability benefits. The reason for this is clearly related to the age and sex distribution of individuals who are eligible under this program, since it does not include individuals where the impact of certain types of crippling arthritis are most heavily felt. Only 18 percent of the individuals in this program were under the age of 50 years, and only 20 percent were women. Of the applicants for Social Security disability benefits, 56 percent had osteoarthritis and 27 percent had rheumatoid arthritis (1). A National Health Education Committee, in Washington, D. C., estimated that each year 320,000 persons in the United States are rendered totally unemployable by rheumatic diseases. While more accurate data is certainly desirable, there is no question that this Workshop is dealing with a problem of considerable magnitude.

There are at least forty different forms of arthritis and related diseases that can lead to temporary or protracted disability, or to permanent crippling. Of these, the one that bulks largest, in terms of human suffering, that is characterized by a pro-

tracted or recurrent course, and that possesses the greatest capacity for producing irreversible crippling is rheumatoid arthritis. While osteoarthritis is, statistically, a more common disease (indeed, technically almost every individual who is over the age of 40 can be regarded as having some degree of osteoarthritis) this condition is very gradual in its onset and progression. It permits adaptation of the patient's level of activity over a long period of time and rarely causes a severe degree of difficulty. In contrast, rheumatoid arthritis strikes unpredictably. It affects a younger age group at the time of maximum responsibility, in family relationships, striking the wage earner in his most productive years and the housewife at times of maximum family responsibilities.

Specific infections of the joint and gout can also cause crippling, but in these situations effective medical management is well defined and the primary problems are accurate diagnosis and patient cooperation. A variety of forms of nonarticular rheumatism may cause temporary disability of considerable magnitude, but these conditions, in a great majority of cases, are limited to a few weeks or months in duration; and, with proper management, they

should not result in irreversible crippling. Therefore, in this Workshop, rheumatoid arthritis may be regarded as the prototype of the crippling diseases, not only because it is the least well understood and the most difficult to manage, from the medical point of view, but also because of its important impact on the individual, on his family, and on his ability to function in society.

Also pertinent to the purpose of this Workshop is the fact that any sound program that is developed to meet the problem of disability from rheumatoid arthritis will automatically include the measures that can be brought to bear on other forms of disability from rheumatic diseases. Indeed, it would be virtually impossible to develop an adequate program for rheumatoid arthritis that would not accomplish this purpose.

Basic Considerations

In the prevention of disability from rheumatoid arthritis, there is one fact that has been repeatedly demonstrated and agreed upon by virtually all workers in the field—the importance of early hospitalization and subsequent medical and social support. A powerful argument can be made in favor of hospital treatment early in the course of rheumatoid arthritis and for the

provision of adequate medical and social supervision, on a long-term basis, following discharge from the hospital. It is clear that these measures are important in the maintenance of the functional ability of patients with rheumatoid arthritis and, therefore, in the prevention of disability and crippling from this disease.

The importance of early hospitalization was clearly outlined by Short and Bauer and their associates (2), and it has been repeatedly confirmed in additional studies. All of these studies indicate, clearly, that the course of the disease is better in those patients who are admitted to the hospital within one year of onset of their disease. Because of the importance of this thesis to the subject of this Workshop, it is worthwhile to look at, in some detail, at least one of these studies.

The most recently reported study (3, 4, 5) consisted of an original group of 307 admissions to the Rheumatism Unit of the Northern General Hospital in Edinburgh, Scotland, between June 1948 and July 1951. Admission to the hospital had been decided upon because of active disease, the presence of deformities, or both. The mean duration of stay in the hospital was 9.4 weeks. While in the hospital, all the pa-

tients were put under the same basic regimen, which was comprised of rest in bed, the application of plaster splints to affected joints, aspirin to limits of tolerance, physiotherapy, and a graduated return to the highest attainable functional level. Drugs other than aspirin were avoided. After discharge, the patients were seen at regular intervals and their treatment was modified as the need arose. Splints were removed and help was provided in domestic and employment problems. At this stage, drugs were given whenever they were indicated.

Careful assessment of disease activity and functional capacity was made at the time of admission to the hospital, at the time of discharge from the hospital, and at intervals of two, four, six, and nine years following discharge from the hospital. Of the 200 survivors who were available for assessment some nine years after discharge from hospital, 20.5 percent were without significant residual disability, 41 percent were moderately incapacitated, 27 percent were more severely crippled, and 11.5 percent had become entirely dependent on others.

Between discharge from the hospital and the first assessment, some two years later, the overall pattern reflected maintenance of

nearly all the improvement that had occurred during hospitalization, with an overall pattern of some further improvement. From two years onward, there was a gradual but progressive deterioration in the functional status of the group, as a whole, due, in part, at least, to increasing age and degenerative changes in previously damaged joints. The disease remained moderately active in the majority of patients throughout the period of observation, but functional capacity and the capacity for useful employment was reasonably well maintained among the survivors.

A study of social and economic factors indicated a close relationship between domestic or financial difficulties and the degree of crippling, as might be expected; but the relatively small number of unresolved problems in the last assessment was a clear indication of the important part that is played by medical social workers in the long-term care of the disabled. Maintenance or loss of morale was also intimately related to the degree of disability.

The group that showed the greatest initial improvement was comprised of those whose musculature was likely to be most efficient—the young, rather than the old,

men, rather than women, and manual, rather than sedentary workers. This, as well as other observations, would suggest that benefit that was derived from treatment was more attributable to the physical measures that were used in the maintenance of function than to the effectiveness of measures that were directed toward reduction of disease activity.

There are two points that must be kept in mind in generalizing from studies of this sort. The conclusions, with respect to the course and prognosis of rheumatoid arthritis, are naturally based on cases that are severe enough to be selected for hospital treatment. They do not necessarily apply to the milder cases, with little or no disability, which may never be referred to a hospital. Several surveys indicate that such mild cases, with little or no disability, make up a considerable portion of the total number of people with rheumatoid arthritis in the whole population.

It must also be borne in mind that the death rate among such groups of patients with rheumatoid arthritis is higher than in the general population, in all ages and in both sexes, although the causes of death do not appear to differ from the expected pattern. Mortality is highest among those

most severely affected by rheumatoid arthritis. The fact must be borne in mind in reviewing late followup results, since the removal of the more severely affected segment of the group may give rise to an over-optimistic view of the long-range results.

Objectives

In order to make available to all patients with rheumatoid arthritis the advantages of early hospitalization, combined with subsequent careful medical and social supervision, effort must be directed toward at least three objectives:

- A. Acceptance by the patient and by the general medical profession of the fact that early intensive treatment is both necessary and of value. This involves a public education program, as well as an education program for physicians and for paramedical workers. It also underscores the necessity for early and accurate diagnosis, with the associated responsibility of insuring that facilities for early and accurate diagnosis are available.
- B. Availability and adequacy of facilities for hospitalization. This clearly involves a significant economic problem.

In addition, it is important that optimal facilities be available, in terms of both trained personnel and physical resources, to provide the services that are needed for the arthritic patients. Required are physicians who are skilled in the medical, orthopedic, and physical medicine aspects of rheumatic diseases. Required, also, are the special skills and experience of physical therapists, social service workers, nursing personnel, occupational therapists, nutritionists, and dietitians. A soundly based program must, clearly, be involved with the training of such individuals, as well as with their appropriate utilization.

- C. Availability and adequacy of resources for the medical and social supervision that must follow the period of intensive treatment during hospitalization and, also, for those patients whose disease is not severe enough to require hospitalization. This involves the establishment, distribution, and setting of proper standards for arthritis clinics, in order to provide the necessary medical supervision. It also involves the services of all of the paramedical professions who are concerned with the

hospitalization facilities that are listed above. To be successful, this aspect of the program must also enlist the services of many agencies, such as public health nurses, visiting nurses, vocational and recreational programs, and rehabilitation efforts, which are not directed primarily at the arthritic patient. Although the efforts of these organizations are not restricted to patients with arthritis, they have much to offer in terms of both experience and objectives, which can be beneficial to the achievement of the ultimate goal of preventing disability from rheumatic diseases.

It is the specific assignment of this Workshop to review the present activities and programs of voluntary and public agencies, with the objective of determining what is being done at the present time and how these programs and activities can be made more effective.

Voluntary Agencies that are Concerned with Arthritis

The Arthritis Foundation. Within the past year, The Arthritis Foundation has emerged as the voluntary agency that is concerned with both the professional and

the lay effort in the field of rheumatic diseases. Formerly, the Arthritis and Rheumatism Foundation, its national program is concerned, primarily, with both lay and professional education. Through its regional chapters, it is directly involved in the support of arthritis clinics and in the administration of other facilities that bear directly on the care of the arthritic patient. Its organization is closely intertwined with that of the American Rheumatism Association (now, the Rheumatism Section of The Arthritis Foundation), as far as professional guidance and policies are concerned. Currently, efforts are underway to make the coordination of the lay and professional medical effort in this field still more effective. The National Foundation, which previously had a program in arthritis that was directed particularly toward juvenile rheumatoid arthritis, has concentrated in other areas since the emergence of The Arthritis Foundation as the strong voluntary organization.

The Rheumatism Section of The Arthritis Foundation (formerly, American Rheumatism Association). This is the professional organization of physicians who have a special interest in the field of rheu-

matic diseases. It currently numbers more than 1,600 members. It provides leadership in professional education and furnishes professional resources and "know-how" to public education programs of The Arthritis Foundation.

Community Hospitals and Medical Centers. There is an accelerating tendency for the hospital to become the focal point in the provision of all aspects of medical care. This is true with respect to both diagnostic resources and treatment facilities. In addition, because the hospital supplies a setting in which the physician can function most effectively and efficiently, it is often only in the hospital that the more refined diagnostic procedures are available. The hospital is the setting in which the physical therapist, dietitian, occupational therapist, and social service worker can function most effectively; indeed, in all but a few areas, it is the only place where such individuals and facilities are available. Through their internship and residency training programs, these hospitals exert an important influence on professional education. They are also often the focal point in the training of the paramedical professions, whose services are so important in the care of the arthritic patient.

Hospitals that are associated or affiliated with medical schools and medical centers are involved in direct service to patients to the extent that they function to meet community needs. They also serve an important function in the training of individuals in the medical and paramedical professions and in the demonstration of effective organizations and procedures in meeting the needs of the arthritic patient.

Arthritis clinics have tended to develop entirely in relationship to hospitals—most frequently, in relationship to hospitals that are concerned with teaching and residency training. The National Foundation pioneered in the financial support of arthritis centers that serve as demonstration units, and it is projected that continuing efforts in this area will be supported by The Arthritis Foundation.

The outpatient department of the hospital plays a particularly important role in dealing with the problem of arthritis, since there is need for continuing medical supervision, as well as for episodes of hospitalization.

Other Voluntary Agencies. Numerous agencies that are concerned with the problems of chronic incapacitating disease include patients with arthritis in their pro-

grams. In many areas, such programs as visiting nursing programs are coordinated and, to some extent, supported by the activities of the chapters of The Arthritis Foundation. In many areas, there is a lack of effective coordination of these programs into the effort to improve care of arthritic patients.

Public Agencies that are Concerned with Arthritis Programs

The United States Public Health Service
The Bureau of State Services, through its Division of Chronic Diseases, has a combined Diabetes and Arthritis Program, which is responsible for the efforts of the United States Public Health Service in the arthritis field at a national level. The activities of this Program have ranged from the preparation and dissemination of material for public education to the preparation of recommendations for community arthritis projects and programs in county and local health departments. Its public education activities have been closely coordinated with those of The Arthritis Foundation. In some areas, it has cooperated with State health departments and chapters of The Arthritis Foundation to sponsor symposia, postgraduate courses, and demonstration programs to provide improved

facilities for the care of the arthritis patient. The primary charge of this program is to seek more expeditious application of the scientific techniques we now know and of those that are becoming available through research.

National Institutes of Health (National Institute of Arthritis and Metabolic Diseases). This research arm of the United States Public Health Service supports a large program for research in arthritis and for the training of research workers in this field. While programs of this Institute may not be directed immediately to the care of the arthritic patient, they indirectly exert an important influence on professional education and in the development of facilities for patient care. The centers for research and training in research are located in the same institutions that are providing leadership in the development of facilities for care of the arthritic patient. There is a fine tradition of cooperation between the National Institute of Arthritis and Metabolic Diseases and The Arthritis Foundation.

State Health Departments. In most State health departments, no specific activities are directed solely to arthritis. Most State health departments support a

number of projects, throughout the State, that directly or indirectly influence care for the arthritic patient. These may include chronic disease diagnostic clinics, rehabilitation centers and services, nursing services to the chronically ill, stimulation of home-care services, with available consultation subsidization, homemaker services, and nursing home services. Programs that are concerned with facilities for the care of crippled children and crippled and afflicted adults may include appropriate patients and arthritis.

It is apparent that in several States the activities of the State health departments are closely coordinated with those of the chapters of The Arthritis Foundation. Such activities may include symposia and dissemination of literature for public education, the joint sponsoring of symposia for physician education and, also, for the education of nurses, physical therapists, and social service workers, and the preparation of a directory of arthritis services that are available throughout the state. In several States, key staff members of the appropriate division of the State health department are members of the Medical and Scientific Committee of the State chapter of The Arthritis Foundation.

Examples of Activities in Which State Health Departments Have Provided Leadership or Have Participated

Pennsylvania: In cooperation with the Pennsylvania chapters of The Arthritis Foundation, two State conferences on arthritis have been conducted for medical and paramedical groups. Seven institutes on diet and arthritis have been conducted. Equipment has been made available for physiotherapy demonstration projects. Institutes on rehabilitation and restorative services have been conducted. Training programs in rehabilitation have been conducted for nursing home staffs.

New Jersey: Program activities include promoting community resources for control of arthritis, including continuity of care services, rehabilitation services, and diagnostic services. The department has encouraged and facilitated research studies and provided education in arthritis and allied disorders. Arthritis symposia have been sponsored jointly by the State health department, medical school, and county hospitals. The State health department has prepared a directory of arthritis services that are available in New Jersey, including agencies, clinics, educational materials,

physical medicine, and rehabilitation resources.

Colorado: The State health department cosponsored a three-day institute on "Management and Rehabilitation of Patients with Arthritis" with the Rocky Mountain Chapter of The Arthritis Foundation, the University of Colorado Medical School, and the State department of rehabilitation. Plans were formulated to provide assistance to the Rocky Mountain Chapter of the AF for purchase of equipment for physical therapy home service programs and craft rehabilitation projects. Assistance is also being developed for professional lay education through the procurement and utilization of educational materials and audio-visual aids. Other services relate to consultation to nursing home administrators, including occupational and physical therapy consultants, community homemaker services in Denver, and extension of programs for home nursing care of the sick.

Kansas: Courses sponsored in self-help and rehabilitation for nursing home personnel include service to arthritics, as well as to stroke patients. Rehabilitation courses are conducted for registered nurses. Also programs for nursing care of the sick at home are being developed. The

Kansas statewide arthritis education program is a cooperative agreement involving the Kansas Chapter of The Arthritis Foundation, the Kansas State Health Department, and the U.S. Public Health Service. The objectives of this program are to provide up-to-date information to physicians and paramedical personnel on techniques, particularly physical therapy, that are used for care of arthritics. It also seeks to organize and mobilize community resources to improve the care of the arthritic.

Minnesota: A project entitled "Home Economists in Rehabilitation" has been sponsored jointly by the State health department, the Minnesota Heart Association, the State agricultural extension service, and the Minnesota Chapter of The Arthritis Foundation. This is a project to assist homemakers with physical handicaps to accept the knowledge that will encourage them to develop both realistic attitudes toward homemaking and enable them to accomplish some, or all, of their homemaking tasks. A series of four classes are held. They cover different aspects of homemaking. This program reached about 160 homemakers in 13 counties in 1963.

County and Community Health Departments. It is difficult to get significant in-

formation about the activities of county or community health departments in the field of arthritis. It is clear that such health departments are in a position to play a key role in community arthritis projects.

An example of the way in which rehabilitation services to arthritis patients has been extended by a generalized public health nursing agency is provided by Tulsa's arthritis program. The first steps were to ascertain the number of rheumatic disease victims in the community who required home nursing service and to decide on the type of inservice education that would best prepare the nursing division of the City or County health department to take care of them. On the basis of the information and prior experience of a specialized program that had been established by the local chapter of The Arthritis Foundation, the staff nurses became acquainted with the patients, familiarized themselves with the patient's disabilities, and gained considerable insight into the needs of these patients, with respect to the medical, nursing, and physical therapy techniques that are needed. This was followed by formal lectures and demonstrations and the participation of staff nurses in training programs that were available elsewhere. It

is of interest that, in one year, about 12 percent of 7,620 visits for nursing care in the home were made to arthritic patients. During the same year, 191 new arthritic patients were admitted to the nursing service.

There are also a number of both governmentally supported and voluntary organizations that are concerned with the provision of diagnostic, treatment, and rehabilitation programs for the chronically ill patient at the community, regional, and national levels, with programs and facilities that play an important role in services that are available to the patient with arthritis. One of the purposes of this conference will be to obtain more information concerning such programs and to develop recommendations for more comprehensive and extended care of the arthritic patient, through coordinated health activities and through the integration of health information.

Educational Activities of Voluntary and Public Agencies

Public Education. A sound pattern for the provision of authoritative information on arthritis has developed, usually with The Arthritis Foundation taking leadership in preparing appropriate literature, fre-

quently with the advice or participation of committees of the Rheumatism Section of The Arthritis Foundation (formerly, American Rheumatism Association). Dissemination of this information is carried on, to a considerable extent, through the chapters of The Arthritis Foundation, the Division of Chronic Diseases of the United States Public Health Service, and the State health departments. Examples are the booklet entitled, "Strike Back at Arthritis," informational booklets about quackery in the arthritis field, and authoritative information about fact and fancy and the relationship of diet to arthritis. The Arthritis Foundation also prepares and distributes informational pamphlets, directed toward the education of the patient that is afflicted with arthritis, that deal with the various types of rheumatic diseases.

Professional Education. Several organizations are concerned with keeping the medical profession up-to-date on advances in the diagnosis and management of arthritic disease. These efforts are usually well coordinated, and several of them are undertaken on a cooperative basis. An example is the "Primer on Rheumatic Diseases," which is prepared periodically by a committee of the Rheumatism Section of

The Arthritis Foundation and published in the *Journal of the American Medical Association*. Through The Arthritis Foundation, copies are distributed to every medical student in his junior or senior year in medical schools throughout the United States and Canada. Information concerning advances in research are disseminated in the monthly *Bulletin of Rheumatic Diseases*, a joint enterprise of the National Institute of Arthritis and Metabolic Diseases and The Arthritis Foundation, which is distributed to approximately 60,000 practicing physicians in the United States, primarily through the chapters of the Arthritis Foundation. A periodic *Rheumatism Review*, prepared by a committee of the Rheumatism Section of The Arthritis Foundation, is widely distributed with the financial support of The Arthritis Foundation. Symposia and postgraduate courses that deal with the diagnosis and management of the arthritic are frequently cosponsored or organized by the Rheumatism Section of The Arthritis Foundation, or its regional affiliated societies, and The Arthritis Foundation and its chapters, sometimes, with the joint sponsorship of the State health department.

Education of Clinical Specialists in

Arthritis. There has been a substantial increase, in the last fifteen years, in opportunities for advanced training for physicians who wish to concentrate in the field of rheumatic diseases. This has tended to occur, particularly, in centers in which there is an ongoing research program. It has been stimulated by the training grants program of the National Institute of Arthritis and Metabolic Diseases (PHS). However, since such training grants have concentrated in the training of younger physicians for research in the field of rheumatic diseases, there has been a real problem, financially, in providing training for men who are not primarily interested in research, but who wish to develop their proficiency in the diagnosis and management of the arthritic patient. The Arthritis Foundation, both at the national level and through its local chapters, has tried to meet this need to a limited extent. There is a very real need for financial support for men who are seeking advanced training in this field in order that they may be better prepared to provide care for the arthritic patient.

We are not aware of comparable training opportunities for the other professions that are concerned with providing health

care. Chapters of The Arthritis Foundation and governmental health agencies have organized one and two-day symposia to provide public health nurses, visiting nurses, nutritionists, physical therapists, social service workers, vocational, recreational, and social rehabilitation workers with some information concerning the particular problems of the arthritic. Most of the real experts in these paramedical professions, as far as the arthritic patient is concerned, have developed through "on the job training" by participating in the activities of an arthritis center, rather than through an organized program of training.

Hospitalization Problems

Organizational and Financial Considerations. Both hospital organization and planning and the patterns of defraying the costs of hospitalization in this country have tended to center on care for the patient with acute illness. There is a limitation to the extent to which such patterns can be adapted to the needs of the patient with chronic disabling disease. Physical facilities and administrative organizations, which are quite suitable for the care of patients who are hospitalized for a week or two, are often not appropriate for providing optimum

care for patients whose hospitalization is a matter of months. Similarly, hospitalization insurance plans, which are adequate in meeting the cost of acute illness, are inadequate when applied to patients who require long-term hospitalization.

Hospitalization programs for the arthritic patient have tended to develop in training centers, usually in connection with medical schools. The problems that were cited above become more pertinent if recommendations are considered for the extension of the development of such resources in the community and voluntary hospitals. An easy solution might appear to be the development of hospital facilities that are designed, organized, and financed to meet the specific needs of the arthritic patient. But there are obvious disadvantages in the development of such facilities: They tend to become isolated from the mainstream of medical progress and care, and they are difficult to integrate with followup services that are much more likely to be part of an overall community or regional program.

It is apparent that those who set out to make realistic recommendations for providing adequate hospitalization facilities for patients with arthritis must weigh the

above considerations carefully.

Standards of Excellence in Hospitalization Resources. The most important aspect of the quality of care that is provided during the hospitalization of patients with arthritis is clearly dependent on the professional qualifications of the staff. In addition to the general diagnostic and consultation services that are usually found in a general hospital, the special skills of men who are trained in rheumatology, orthopedic surgery, and physical medicine are required. Special training is also needed in the paramedical health professions that are concerned with the care of such patients. These include nursing, social service, vocational rehabilitation, and psychological testing workers. The public and voluntary agencies can be most effective in providing support for the training of such individuals, and also in insuring adequate budgetary provision for the variety of skills that must be brought to bear in the care of the arthritic patient.

Continuing Medical and Social Supervision

Continuing medical and social supervision is usually provided by outpatient clinics that are closely affiliated with the institution that is providing the resources

for hospitalization of the arthritic patient. It is clear that the organizational and financial problems, as well as the maintenance of quality in such continuing activities, are dependent on much the same factors as those that were outlined above, under the heading of hospitalization. However, it is in this area of continuing supervision that the role of the physician becomes less predominant and dependence on adequate programs in the home nursing, physical medicine, and social aspects become increasingly important. It is also in this area that integration with other community programs that deal with the chronically ill patient can be most effectively utilized.

Currently, most of the activities that are directed toward this aspect of the care of the arthritic patient have developed through the local and regional chapters of The Arthritis Foundation. Such activities have included aid in the establishment and continuing support of arthritis clinics; the provision of physical therapists to work with the visiting nurses' and public health nurses' programs; financial aid in the provision of corrective supports, splints, and wheel chairs to severely handicapped individuals; the maintenance of mobile physical therapy units for the homebound arthritic; and

participation in community homemaker, recreational, rehabilitation, and home nursing efforts. The Arthritis Foundation has developed a set of recommendations for standards for the organization and operation of such arthritis clinics.

Summary

Today, we, in this country, can bring excellent resources to bear on the problems of prevention of disability from rheumatic diseases. A significant segment of the medical profession is interested in rheumatology; nearly 2,000 members of that profession are organized into an effective, professional organization. We have a strong and outstanding voluntary health agency that is concerned with the problem. Our research activities are the envy of the rest of the world, and we have a preponderance of eminent investigators and clinicians in the field of rheumatic diseases. There is a focus of special interest in rheumatic diseases in nearly two-thirds of our medical schools, and there are over three hundred special clinics for patients who suffer from these diseases. The U. S. Public Health Service is committed to helping the American people find the answer to chronic disease, and State and local health authorities are dedicated to serving the health

interests of those for whom they are responsible. And regional and community organizations are concerned with the medical and social aspects of chronic incapacitating disease. With stronger interaction and liaison between these groups, advances can be made "which will convert the problem of rheumatic disorders from a public liability to an area of competence in disease control, rehabilitation and prevention of disability." (6)

Bibliography

1. Roemmich, W.: Disability and rheumatic diseases: social security data. *Arch. Environmental Health* (Chicago) 4:490, 1962.
2. Short, C.L. and Bauer, W.: The course of rheumatoid arthritis in patients receiving simple medical and orthopedic measures. *New England J. Med.* 238:142, Jan. 1948. Also Short, C.L., Bauer, W., and Ropes, M.W.: *Rheumatoid Arthritis*. Harvard Univ. Press, Cambridge, Mass., 1957.
3. Duthie, J.J.R., Thompson, M., Weir, M.M. and Fletcher, W.B.: Medical and social aspects of the treatment of rheumatoid arthritis, *Ann. Rheumat. Dis.* 14:133, June 1955.
4. Duthie, J.J.R., Brown, P.E., Knox, J.D.E. and Thompson, M.: Course and prognosis in rheumatoid arthritis. *Ann. Rheumat. Dis.* 16:411, Dec. 1957.

5. Duthie, J.J.R., Brown, P.E., Truelove, L.H., Barager, F.D. and Lawry, A.J.: Course and prognosis in rheumatoid arthritis. *Ann. Rheumat. Dis.* 23:193-204, May 1964.
6. McDonald, O.H. and Penn, I.M.: Tulsa's Arthritis Program. *Nursing Outlook*, Vol. 10, Sept., 1962.
7. Edwards, M.H.: National and International Review of Arthritis Programs: Conference on Arthritis as a Public Health Problem, Houston, Texas, Feb. 4 and 5, 1964. U. S. Public Health Service, Division Chronic Diseases, Washington, D. C. 20201.

Workshop 7

Socioeconomic Aspects (Financial Resources)

Ronald W. Lamont-Havers, M.D., Chairman

Arthritis has been a problem with which the individual patient and his immediate family have had to cope since antiquity. Today, however, the impact of arthritis is so great that it has become, in addition, a public health problem of major importance to the Nation, as well as to individual com-

munities. This is well illustrated in the selected statistical data that is available.

These statistics must be interpreted, however, with an understanding of the many factors that are involved in their compilation. Some of these will be explored during the Workshop session.

Arthritis patients seldom have arthritis as their only problem. The general age group is such that other chronic and acute diseases as well as the infirmities of age, are frequently concomitant companions. Invariably, the psychosocial consequences of the disease are a major burden. These multiple problems must be taken into consideration. In many respects, therefore, the study of arthritis can be viewed as the prototype of studies of chronic disease problems that normally face the community.

The clinical aspects of arthritis and the rheumatic diseases generally will not be discussed. Background information on this aspect can be obtained from the "Primer on the Rheumatic Diseases." Of all the various diseases that are classified under the rheumatic diseases, those of greatest socioeconomic importance are rheumatoid arthritis and osteoarthritis.

Other sections of the Workshop will be discussing many of the problems that con-

front the individual and the community, from the standpoint of needed facilities and personnel. This Workshop on socioeconomic aspects will concentrate, primarily, on the problems that are associated with the major economic impact of arthritis upon the patient and the community.

It is expected that a number of areas that are in need of additional study and information will be identified. Typical of these areas are the following: The need for assessing services and facilities for the arthritic in the local community; the difficult problem of implementing actions so noted; and the manner in which the unique needs of the arthritis patient and of those with chronic disease, generally, can be integrated into the present health care plans.



Workshop Reports and Discussions

Public Education and Information

Chairman: William S. Clark, M.D.

The effect of crippling arthritis on the Nation's health and economy constitutes an emergency that the public can no longer ignore. Arthritis is the Nation's number one crippling disease. It exacts an enormous toll in human and material resources.

Arthritis is a growing and spreading problem. Something can be done about it now. Intensified and sustained programs of public education and information are essential to the achievement of effective control of the crippling effects of all major forms of arthritis.

The extraordinary amount of personal disability and the burdensome cost of the

individual to his family, to the community, and to the Nation that result from arthritis can be attributed, in part, to the general lack of information and the considerable abundance of misinformation about the nature of the arthritic diseases. It can be attributed, also, to the lack of motivation to develop and utilize optimal professional skills, meaningful facilities, and resources for treatment and care.

Moreover, misconceptions about arthritis are being perpetuated by counter propaganda for the promotion of legitimate and fraudulent treatments for arthritis. Public education cannot be clearly separated from professional education, either in concept or in practice. As one panelist put it: Every physician is a layman in some area of the medical sciences.

Moreover, the level of information of the general public is proportionate to the degree of professional knowledge. The subject, Public Education and Information, could well be included on the agenda of each of the six other panels that are arranged for this conference.

Responsibility for public education and information rests with all agencies that are concerned with the problem of arthritis, as well as with individuals in the medical

and paramedical specialties who are involved in the care of the arthritic patient. Public education cannot take place in a vacuum. It must begin with the patient and relate to meaningful and attractive services that are available for effective treatment.

In this discussion, we will consider the patient to be a part of the public. A high priority objective in the prevention of crippling arthritis is bringing the patient into points of contact with skillful professional personnel and effective medical facilities.

The purposes of public education and information can be stated as follows: The goal of the effort against arthritis is to reduce or prevent disability in its victims now and, as soon as possible, to develop techniques for cure or total prevention.

Our Workshop believes that there is substantial factual information on arthritis that is not now reaching patients and the rest of the public. We believe that bringing such information, in a proper way, to those who need it can motivate them and influence their behavior, thus contributing toward a solution of the problem of arthritis.

The public information program for arthritis should include the following pur-

poses: To motivate those with arthritis to seek qualified medical care, to seek it sooner than they might otherwise, and to stick with it; to improve attitudes toward arthritis and the arthritic individual, replacing despair with justified hope; to motivate educators at all levels to pay more attention to arthritis; to create in the public an awareness of the size and seriousness of the arthritic problem (it being noted that the decisions of individuals who are not physicians, but who serve on hospital boards, or on legislative bodies, or who support and participate in voluntary organizations, will largely determine what will actually be done about arthritis); to stimulate widespread interest in a major effort against arthritis and in the challenge the problem poses.

The Workshop notes that while doctors, nurses, and other health workers are trained by professional educators, it is usually exposure to public information that stimulates them to select their careers.

The more that is said about arthritis in newspapers, in private sayings, in magazines, books, and over radio and television, the more excitement will be generated about it and the more young people will be drawn to careers in it.

What is done in the public sector of information, if done well, can also have a massive impact in the area of improving the amount, quality, and effectiveness of professional education.

Whom to educate . . . The public, at large, including the physician, as well as the layman, is the audience to which public education and information programs on arthritis must be addressed. Programs should be directed to specific groups, physicians, paramedical specialists, educators, pharmacists, community leaders, and others who, in effect, educate or advise the public or mold public opinion.

Certain segments of the arthritis problem have especially pertinent application to certain groups. There is reason for concern about the patient's understanding of his own problem.

Content . . . The public information and education program on the arthritic diseases should contain the following basic elements in its approach:

The public must be made aware that many of the rheumatic diseases are manageable and preventable and that tremendous public health problems have been conquered by their demand.

The importance of early diagnosis must

be continually emphasized. With proper medical care, severe crippling can be prevented in most cases of arthritis, and most patients are able to maintain significant measures of function, or significant measures of independence, regardless of the stage of progress of the disease or the severity. Lost function can be retained or, to a great extent, restored.

Treatment must be administered by qualified physicians; and it should be the policy of public education programs to identify and explain the elements of adequate care. These include regulation of physical activity and environment, proper diet guidance when appropriate, proper selection and administration of drugs, the use of physical medicine, and specialized care, such as orthopedic surgery, psychiatric treatment, and rehabilitation techniques.

Methods and techniques . . . The development and support of a trained administrative staff and personnel for planning, implementation, and continuity is essential. There must be national, State, and community programs of information and education about arthritis.

There must be development of sources of information and cadres of individuals

to convey information through a variety of conference and group techniques, including neighborhood and patient group discussions.

There must be development and selective utilization of audience-specific terms. There must be development of interest and support by mass media for comprehensive educational programs for arthritis care.

Conclusions and recommendations: It is the consensus and unanimous agreement of our group that more money should be invested in public education and information by all agencies. There must be a continuing and sustained effort. There must be education of a special group of people who need information in depth to act in the capacity of educators and informers.

There must be research in the motivation of patients to seek and to accept adequate treatment; and there must be research in the comprehension of the informational materials that are supplied to patients, their families, and the public.

There must be intensified programs and expansion of existing programs. There must be cooperation among agencies and the avoidance of duplication; and we must encourage greater involvement of all media in the problem.

For the discussion, I have asked the four people who helped prepare this report to sit at this table and help me answer questions, because I don't want to do all the talking.

Discussion

DR. McDONALD: I have no questions, only a comment; and it is complimentary to the group that you represent. I think that this was a very good statement, and that it will help to guide our Program in the next several years. Thank you very much for this report.

DR. WILLIAM CLARK: Thank you for the gracious comments, Glen.

DR. TRAEGER: When you talk of continuity, just what do you mean?

DR. WILLIAM CLARK: We mean that this shouldn't be a short burst, a one-shot affair, that it should be a sustained program and that there should be continuity of knowledge, objectives, and planning.

We are not talking about a project for 1965. And programs in public education must be adapted to increasing knowledge, not only to knowledge about the nature of arthritis diseases, but about the patient and the public's acceptance of this knowledge and about their motivation to act on the problem.

DR. STILLMAN: I think that you have done such a superb job that I have nothing to add. I congratulate you and your committee.

DR. DECKER: Did the committee talk about over-publication to the general public of investigative advances that are not, perhaps, pertinent to the status of any one individual, but which can give him major hunks of unfortunate information?

DR. WILLIAM CLARK: I don't know that I understand the question, but I am going to let someone over here answer it. Dave, do you want to take a crack at it? Incidentally, my panel is, from my left to my right, Mr. David Preston, science writer, Dr. Theodore Bayles, Director of Research, Robert B. Brigham Hospital in Boston, Mr. Lee Curren, Director of Public Information of The Arthritis Foundation, and Dr. Ralph Jacox, Dept. of Medicine, University of Rochester. Mr. Preston will answer.

MR. PRESTON: The committee did not specifically talk about that problem, but I think it was the consensus of the committee that we need a lot of specific material for people with specific arthritic diseases and conditions.

I think that if those materials were well

enough prepared and if they met the need, the individual patient would not be likely to be led astray by an occasional story of the kind of which you are thinking.

DR. WILLIAM CLARK: Such as DMSO.

MR. FRALEY: I think that this ties in with what Dr. Traeger said—that you have to raise the level of knowledge in the general public continuously, on a sustained basis, so that when there is premature publicity the general public has some kind of background in which to judge any specific piece of information.

DR. JACOX: I think our committee did devote considerable discussion to the education of the patient as being an important way to make them less vulnerable to these ill-advised press releases. And our committee felt, generally, that if the patient had a good knowledge of his or her disease, he would not only cooperate more readily with treatment suggestion, but he would be in a much better position to read things, perhaps, that come out in the newspapers about arthritis.

DR. JOHNSON: I am concerned about the prevalent—and I say that guardedly—idea that prevails among physicians who are rendering firstline medical care to peo-

ple who have this crippling disease—nothing can be done for the arthritic.

I see arthritics in my office and in other areas who were told, one, two or three years before they came to me, that they had one of the arthritides and that there was nothing that could be done for them. They had gone home and slipped into the passive and recessive group. They had accepted it.

How can you tell these people that, regardless of the fact that one person in medicine told them nothing can be done, they should seek a physician who is interested in the process and who wants to get something done for them? Is not that in your purvey of services here?

DR. WILLIAM CLARK: Yes, sir. We would like to respond to that, Dr. Johnson. Dr. Bayles?

DR. BAYLES: Well, I think one thing that came out of our discussion was that public education and information had to be across the board. We even decided that doctors were people, that nurses were people, that physical therapists and other health workers were people, that high school students and college students were people, and that junior high school students were people. We had the strong

conviction that this kind of approach of public education and information, while it may be layered to different levels of reception, is an important function.

Mr. Fraley and our other science writers pointed out that we have to adjust the information to the people who are receiving it. And I think, in answer to this, we would feel that the doctor who has told the patient that there is nothing to do about arthritis needs as much education as the arthritic patient, his family, the public, or those whom Bill Clark calls opinion molders in the community.

So, I think it can be said that we are not neglecting any category of individuals; and we hope that we can reach, with different material, hopefully, every strata, or every phase of people, as we call them, in our country.

DR. WILLIAM CLARK: We emphasize that public education begins with the patient and with those who are responsible for the patient or on whom the patient is dependent for any kind of assistance.

DR. ROBINSON: Mr. Chairman, sometimes one finds that when one has information one thinks is useful for public education, the journalist feels that this doesn't fill the bill because it has no par-

ticular interest to them. Now, I find that this might be exciting news, and they think it is not. We have to get together on these matters. Did the committee consider this?

DR. WILLIAM CLARK: Yes, it did. Dave?

MR. PRESTON: I think that journalists, important as they are, are a small part of the total chain of communication between people who know about arthritis and the patient and the rest of the public.

I think that the journalist has to deal in large measure with what he considers to be new. I think an important message, such as the fact that something can be done about arthritis with what is known now, will have to be delivered to the patient and other segments of the public by many, many means.

It is my own personal guess that if we had complete control of all the science writers and journalists in this country, we would still find that 75 percent of the information on this subject that patients and the public were getting would be coming from other sources.

DR. TOONE: I would like to make a plea for the patient. I think this is the individual who requires our attention and our particular effort. I think it came out

in our discussions that, in many ways, he has been greatly neglected, not only because of our shortcomings in treatment measures, but in the fact that he never was given the proper information about his disease. I think this all points up to the fact that the patient is the individual at whom we need to point most of our attention.

DR. WILLIAM CLARK: I did want to make one other comment and amplify it. Mr. Fraley made the point that we could have sliced this differently and that the public information and education could be a part of each panel discussion. Would you wish to amplify that, Pierre?

MR. FRALEY: No, I think you covered it. I would make a plea, too, that whenever any aspect of this disease, or of the treatment and care that can be given it, is under consideration, that the public information and public educational aspects be taken into consideration.

I am particularly strong on the point that research, for instance, is never done until the results of the research are communicated not only to those people who apply it to patients, but all the way out to the general public.

MR. CURRAN: I agree with Dr. Jacox. It has been a very rewarding session and

I have learned a lot. I think that some of the statements and deliberations of our group will help us at The Arthritis Foundation to broaden our thinking and our programs that bring the facts about arthritis to our people.

DR. BAYLES: Perhaps I had just better point out to the group that we are all going to go home with the responsibility to help in this effort to spread the word, or the party line, or whatever you want to call it.

MR. NILES: I would like to make one comment in amplification of Pete Fraley's comment that educational information must essentially be on a horizontal basis across all of the activities of the other Workshops. From the other Workshops, we will get the tools with which we can work; and Pete Fraley and other science writers and educators, and so forth and so on, can use these tools and apply their skills to hammer these points home.

Also, I think that we did not identify one group in our panel. We identified doctors as people, nurses as people, and so forth, as people. Health educators were identified as those who hold the lantern while their mother chops the wood.

MR. PRESTON: Having been in the

field of science writing for many years, since the time when there was very nearly open warfare between the immediate profession and science writers, it is extremely gratifying to find lay science writers called here by the government to work with doctors and other health professionals to try to solve the problem. I think it is very encouraging.

DR. WILLIAM CLARK: Thank you. That completes our report.

Diagnosis and Treatment Facilities

Chairman: Ephraim P. Engleman, M.D.

Ours, as you know, is the Workshop that was concerned with facilities for diagnosis and short-term treatment. The participants were practicing physicians, fulltime medical academicians, an epidemiologist, a hospital administrator, an expert on automated diagnostic screening, a consultant on community planning, a medical social worker, and a nurse. It was agreed that there is an urgent need for more facilities to permit more widespread early diagnosis and treatment of patients

with arthritis. The immediate questions were: What are the best available methods of diagnosis and treatment? Where can they be found?

It was recognized that proper diagnosis depends on painstaking clinical history and physical examination and on certain laboratory and X-ray findings; that the most effective program for patient management is multidisciplinary and time-consuming; and that optimal methods of diagnosis and treatment are found in certain existing arthritis teaching units. These centers are university-based units, in which knowledge of arthritis is pursued and applied and in which there are personnel and facilities for exemplary diagnosis and patient care, for professional education at both undergraduate and postgraduate levels, and for research.

Prior to World War II, there was only a handful of such centers in the United States; and all were in a few Eastern States. Following World War II, three significant developments made possible establishment of additional arthritis centers that fulfilled the above description: (1) creation of The Arthritis Foundation; (2) establishment of the Training Program in Arthritis of the National Institute of Ar-

thritis and Metabolic Diseases (PHS); and (3) the entry of the National Foundation into the field of arthritis.

Nevertheless, in 1964, when the National Foundation withdrew its support, there were scattered throughout the United States no more than 38 exemplary arthritis centers, of which 17 are currently (1965-1966) supported by The Arthritis Foundation. It is by no means certain that The Arthritis Foundation will be able to continue this support after July 1, 1966. To further compound this problem, there is a critical shortage of arthritis service clinics in the United States. There are only 300 such clinics, approximately one to every 23 accredited hospitals; and in many, the services are inadequate. Recommendations 1 and 2 are designed to preserve existing, qualified arthritis centers and clinics, to upgrade the services of others, and to create new service clinics, as personnel and funds become available.

Recommendation 1. Certain existing arthritis centers should receive continued support to enable them to sustain their exemplary functions. These should be identified as Regional Arthritis Centers and should fulfill criteria and provide services as follows:

- a. They should be university-based, or affiliated with large medical centers, and should provide facilities for professional training and research.
- b. They should be distributed according to geographic and population needs. (See appendix).
- c. They should provide facilities for diagnosis and comprehensive care of outpatients. Comprehensive care includes prevention of disability and provisions for optimal physical restoration, personal and emotional adjustment, and vocational guidance, training, and/or placement of all candidates.
- d. Medical personnel should include a full-time director, who is a physician with training in rheumatic disease, part-time consultants in internal medicine, orthopedics, physical medicine, and pediatrics, and other qualified consultants, when necessary. Trainees, house officers, and students should also attend.
- e. Paramedical personnel should include a physical therapist, a medical social worker, a nurse, a secretary, and other qualified personnel, when necessary. One of these should also serve as the "coordinator of patient services." While these people will work full-time

in the parent institution, all but the coordinator might also contribute to other chronic disease facilities within the institution. The coordinator of patient services, a full-time member of the arthritis center, is defined as one who collaborates with all members of the team in planning the patient's program. He will provide the integration of professional activities that will ensure the provision of diagnostic and treatment services with maximal efficiency and effectiveness. Any one of the paramedical personnel may serve as coordinator, but he must have knowledge of the local health agencies and their services.

- f. Patient services should be readily available and should be utilized effectively. Cordial relations should exist between the center and the sources of patient referral, such as local physicians, arthritis clinics, public agencies, house officers, and others. In addition, the patient admittance policies should be flexible and compatible with those of the parent institution. Consultants should be available within the confines of the clinic. New and problem patients should be seen by both the medical and paramedical staffs, in order to ensure