

FINAL
SUNSET REPORT

*ARIZONA COUNCIL ON ARTHRITIS
AND MUSCULOSKELETAL DISEASES*

1996

*Senate Health Committee of Reference &
House Health Committee of Reference*

**REPORT ON THE ARIZONA COUNCIL ON ARTHRITIS
AND MUSCULOSKELETAL DISEASES**

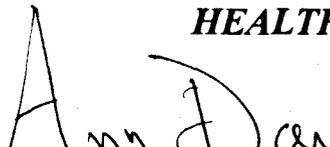
Date: October 23, 1996

To: *JOINT LEGISLATIVE AUDIT COMMITTEE*
Patricia Noland, Co-Chair
Sue Grace, Co-Chair

Pursuant to Title 41, Chapter 27, Arizona Revised Statutes, the Committee of Reference, after performing a sunset review and conducting a public hearing, recommends the following:

The Arizona Council on Arthritis and Musculoskeletal Diseases be terminated.

HEALTH COMMITTEE OF REFERENCE

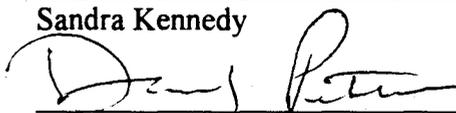


Ann Day, Co-Chair

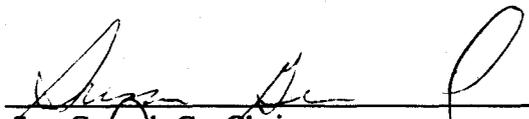
Janice Brewer

James Henderson

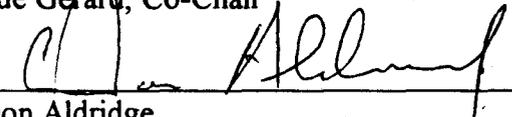
Sandra Kennedy



David Petersen



Sue Gerard, Co-Chair



Don Aldridge



Kathi Foster

Herschella Horton



Lou-Ann Preble

**COMMITTEE OF REFERENCE REPORT
ON THE
ARIZONA COUNCIL ON ARTHRITIS AND MUSCULOSKELETAL DISEASES**

I. BACKGROUND

Pursuant to section 41-2953, Arizona Revised Statutes, the Joint Legislative Audit Committee (JLAC) assigned the sunset review of the Arizona Council on Arthritis and Musculoskeletal Diseases to the Committee of Reference comprised of members of the Senate Health Committee and the House of Representatives Health Committee. A performance audit of the Council was conducted by the Committee of Reference and is included.

II. COMMITTEE SUNSET REVIEW PROCEDURE

The Committee of Reference held one public hearing on Wednesday, October 23, 1996, to consider the sunset report and receive public testimony regarding the Council on Arthritis and Musculoskeletal Diseases. The Committee heard testimony from Pami Kowal, member of the Council on Arthritis and Musculoskeletal Diseases and Bob Gilligan, Legislative Liaison, Arizona Department of Economic Security (DES).

Ms. Kowal testified that the Council pursues legislative activities and community outreach and education. The Council holds public forums in outlying areas to educate people about arthritis and the importance of early detection and treatment. She also emphasized that the Council is a group of close-knit professionals who want to provide support to and collaborate with the Arthritis Foundation, especially in the legislative area to see that arthritis is eradicated and people educated about it. She indicated that the Council has only had a chance to hold one meeting out of six planned for this year. Ms. Kowal urged the Committee to allow the new Council members an opportunity to show the State what it can do by continuing the Council

Mr. Gilligan explained that DES provides a staff person part-time to perform Council duties and that, with per diem and transportation expenses together, the Council's total cost for a year is approximately \$6,000.

III. COMMITTEE RECOMMENDATIONS

The Committee of Reference Recommends that the Arizona Council on Arthritis and Musculoskeletal Diseases be terminated.

IV. STATUTORY REPORT PURSUANT TO SECTION 41-2954 (F), ARS

1. Identification of the Problem or the Needs that the Council is Intended to Address.

The Council on Arthritis and Musculoskeletal Diseases was established in 1987 to address the problem of arthritis and musculoskeletal diseases by bringing together organizations and individuals with a knowledge and basic interest in the area in order to develop recommendations the state may adopt to help meet the needs of victims of these diseases. The Council consists of twenty-one members serving staggered terms of three years each. The Council is required to meet no less than four times a year.

2. A Statement, to the Extent Practicable, in Quantitative and Qualitative Terms, of the Objectives of Such Council and Its Anticipated Accomplishments.

The objectives of the Council are to advise and assist the Governor, Legislature, and all State agencies; submit an annual report and conduct an annual statewide conference; review and make recommendations on plans and strategies; conduct educational programs; serve as a repository of information on arthritis and musculoskeletal diseases; and monitor programs and services ensuring efficient and coordinated use of resources. The Council focuses on the education of the public and health professionals on the problems, issues and developments in the field of arthritis and musculoskeletal diseases.

3. Identification of Any Other Agencies Having Similar, conflicting or Duplicating Objectives.

The Council on Arthritis and Musculoskeletal Diseases coordinates, collaborates, shares members and common goals and objectives with the Arthritis Foundation, a national foundation with regional offices.

4. Assessment of the Consequences of Eliminating the Agency or of Consolidating it with Another Agency.

The Council states that eliminating the Council would reduce the communication, cooperation and collaboration efforts among the numerous organizations serving the culturally diverse and geographically separated members of the arthritis and musculoskeletal diseased community.

The Committee felt that there was no need for the Council and that its function should be handled in the private sector. Specifically, the Arthritis Foundation is performing the same functions.

V. ATTACHMENTS

- A. Cover Letter
- B. Meeting Notice
- C. Performance Audit
- D. Minutes of Committee of Reference Meeting
- E. Attendance List

COVER LETTER

(Section A)



Arizona State Legislature

1700 West Washington

Phoenix, Arizona 85007

June 13, 1996

Ms. Gail Riggs
Arizona Council on Arthritis and
Musculoskeletal Diseases
1789 West Washington, Room 930A
Phoenix, AZ 85007

Dear Ms. Riggs:

The sunset review process prescribed in Title 41, Chapter 27, Arizona Revised Statutes, provides a system for the Legislature to evaluate the need to continue the existence of state agencies. Under the sunset review process, an agency is reviewed by a legislative committee of reference. Upon completion of the sunset review, the committee of reference recommends to continue, revise, consolidate or terminate the agency.

The Joint Legislative Audit Committee (JLAC) has assigned the sunset review of Arizona Council on Arthritis and Musculoskeletal Diseases to the Committee of Reference comprised of members of the Senate **Health** Committee and the House of Representatives **Health** Committee.

ARS section 41-2954 requires the Committee of Reference to consider certain factors in deciding whether to recommend continuance or termination of an agency. Please provide your response to those factors as provided below:

1. The objective and purpose in establishing the Council
2. The effectiveness with which the Council has met its objective and purpose and the efficiency with which it has operated.
3. The extent to which the Council has operated within the public interest.
4. The extent to which rules adopted by the Council are consistent with the legislative mandate.
5. The extent to which the Council has encouraged input from the public before adopting its rules and the extent to which it has informed the public as to its actions and their expected impact on the public.

Arizona Council on Arthritis and Musculoskeletal Diseases

June 13, 1996

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6. The extent to which the Council has been able to investigate and resolve complaints that are within its jurisdiction.

7. The extent to which the attorney general or any other applicable agency of state government has the authority to prosecute actions under the enabling legislation.

8. The extent to which the Council has addressed deficiencies in its enabling statutes which prevent it from fulfilling their statutory mandate.

9. The extent to which changes are necessary in the laws of the Council to adequately comply with the factors listed in this subsection.

10. The extent to which the termination of the Council would significantly harm the public health, safety or welfare.

11. The extent to which the level of regulation exercised by the Council is appropriate and whether less or more stringent levels of regulation would be appropriate.

12. The extent to which the Council has used private contractors in the performances of its duties and how effective use of private contractors could be accomplished.

In addition to responding to the factors in ARS section 41-2954, please provide the committee of reference with copies of minutes from your meetings during fiscal year(s) 1994 through 1996, and an annual report, and respond to the attached questionnaire by **July 30, 1996** so that we may proceed with the sunset review and schedule the required public hearing.

Thank you for your cooperation. Please contact Senate or House health research staff if you have any questions.

Sincerely,

Senator Ann Day
Co-Chair
Health Committee of Reference

Sue Gerard
Co-Chair
Health Committee of Reference

AD/SG/cmh
Attachment
cc: Vincent Kelly, Council Liaison

ARIZONA COUNCIL ON ARTHRITIS AND MUSCULOSKELETAL DISEASES

Please respond to the following questionnaire:

1. Describe the role and function of the council including major activities/projects, accomplishments and obstacles to success.
2. Provide financial data such as number of full time employees, expenditures and revenues and fee structure.
3. Provide information regarding council or board composition including number of members, number of public members and method of appointment.

MEETING NOTICE

(Section B)

ARIZONA STATE LEGISLATURE

MEETING NOTICE

OPEN TO THE PUBLIC

SENATE AND HOUSE HEALTH COMMITTEES OF REFERENCE

SUNSET REVIEWS OF THE

BOARD OF RESPIRATORY CARE EXAMINERS

ARIZONA COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES

**JOINT LEGISLATIVE COMMITTEE FOR THE ARIZONA HEALTH
CARE COST CONTAINMENT SYSTEM (AHCCCS)**

DATE: Wednesday, October 23, 1996

TIME: 9:00 a.m. - Noon

PLACE: Senate Hearing Room 2

AGENDA

- I. Board of Respiratory Care Examiners
- II. AZ Council on Arthritis & Musculoskeletal Diseases
- III. Joint Legislative Committee for AHCCCS

MEMBERS:

Senator Day, Co-chair
Senator Brewer
Senator Petersen
Senator Henderson
Senator Kennedy

Representative Gerard, Co-chair
Representative Aldridge
Representative Preble
Representative Foster
Representative Horton

KB/ak

****Title II of the Americans With Disabilities Act prohibits the Arizona Senate from discriminating on the basis of disability in the provision of its services and public meetings. Individuals with disabilities may request reasonable accommodations, such as interpreters or alternative formats, by contacting the Senate Secretary's Office at (602) 542-4231 (voice) as soon as possible. Please be specific about the agenda item in which you are interested and for which you are requesting an accommodation. The Senate may not be able to provide certain accommodations prior to the meeting unless they are requested a reasonable time in advance of the meeting. This agenda will be made available in an alternative format on request.**

PERFORMANCE AUDIT

(Section C)



GOVERNOR'S COUNCIL ON ARTHRITIS AND MUSCULOSKELETAL DISEASES
1789 West Jefferson - 930A
Phoenix, Arizona 85007

Fife Symington
Governor

Gail Kershner Riggs, MA, CHES
Chairperson

July 26, 1996

(520) 321-0692

Senator Ann Day, Co-chair
Health Committee of Reference
Arizona State Legislature
1700 W. Washington
Phoenix, AZ 85007

Dear Senator Day:

In response to your letter of June 13, 1996 pertaining to the sunset review of the Governor's Council on Arthritis and Musculoskeletal Diseases, here are answers to the questions or topics you inquired about:

1. The objective and purpose in establishing the Council

The Council was established in May 1987 with the purpose of addressing the challenges that individuals who have arthritis and musculoskeletal diseases face in Arizona. The objective of the Council is to develop recommendations for Arizona to consider to help meet the needs of this population. The Council also directly undertakes specific projects designed to provide information and services to persons with arthritis and musculoskeletal diseases, their families, the public at large, and to the professional health community concerned with research or treatment of these ravaging diseases.

Some specific goals the Council has established for itself are:

- to educate the arthritis population on available services;
- to educate the public on the prevention and treatment of arthritis and musculo-skeletal diseases;
- to communicate the needs of persons with arthritis, rheumatism, etc. to the Governor and state agencies, to the legislature and to state committees;
- to advocate for more funding for the prevention and care of arthritis;
- to seek to improve the status of patient care;
to submit proposals for grants for research on arthritis and access to health care;
- to sponsor an epidemiological study of arthritis and musculoskeletal diseases in Arizona.

2. The effectiveness with which the Council has operated within the public interest

The Council has cooperated with private and public agencies involved in the research and/or treatment of arthritis and musculoskeletal diseases in the collection and dissemination of data on the incidence of arthritis in Arizona and the disabling impact it has had upon its victims. The Council has provided some of this information directly to legislators so they can have it in mind when fashioning new health legislation and in assessing budgetary needs relating to the health and well-being of Arizona citizens. The Council has been an effective advocate with the Rehabilitation Services Administration in forming cooperative agreements with various chapters of the Arthritis Foundation in Arizona to provide vocational rehabilitation counseling to persons suffering from the many severe forms of arthritis. This Council has served the vital function of providing communication links among Arthritis Foundation chapters, the University of Arizona Arthritis Center, the Harrington Arthritis Research Center, private arthritis specialists, and regional medical centers around the state.

3. The extent to which the Council has operated within the public interest

The Governor's Council on Arthritis and Musculo-skeletal Diseases has consistently operated in the public's best interest by serving as a catalyst for promoting dialogue among the various state or governmental agencies and those organizations interested in the prevention, treatment or rehabilitation of persons with musculo-skeletal diseases. The Council has consistently advocated to these groups for increased research, prevention, education and improved services to the 606, 367* Arizona residents presently suffering from some form of arthritis or other musculoskeletal disease. Accordingly, the Council provided its support for an epidemiological research grant proposal in October 1993. Council members wrote letters and made personal contact with state legislators in support of RSA's budget requests and advised the DES Rehabilitation Services Administration on opening up the order of selection. They also advocated for state funding of the Disease Prevention Project. Council members have also contacted US Senators and Representatives to support the continuation of a separate agency to provide vocational rehabilitation services. The Council requested funding of research on arthritis from the Arizona Department of Health Services and supported an assistive technology grant proposal by the Institute of Human Development at Northern Arizona University.

The Arthritis Council publicly expressed its support of Governor Symington's opposition to unfunded federal mandates and, in particular, against the federal requirement that RSA provide VR services to SSA recipients for the sole purpose or removing them from SSA roles. The Council on Arthritis and Musculoskeletal Diseases actively recruited the support of state chapters and the national office of the Arthritis Foundation on this issue.

In February 1995 the Council sponsored educational public forums on musculo-skeletal diseases, particularly lupus and multiple myeloma, in South Tucson, Nogales, Sierra Vista and Guadalupe. In March 1996 both a professional and public forum on the role of infection in arthritis were presented in Tucson and Phoenix. In collaboration with the University of Arizona's Arthritis Center and the Arthritis Foundation, the Council has advocated, and will continue to advocate, for a registry of arthritis patients and for improved use of media to publicize important health issues.

Note: *This figure is provided by Dr. Tim Flood, Council member, and researcher at the Arizona Dept. of Health Services, Office of Chronic Disease Epidemiology

4. The extent to which rules adopted by the Council are consistent with the legislative mandate
The by-laws of the Council are in harmony with the legislative mandate. The Council has, however, attempted to influence the legislature to effect changes which would permit the Council to function more effectively: for instance, five appointed members are advisory and cannot vote. Since the Council has a mainly advisory function and has no budget within its control, not allowing some or all of these persons to participate completely weakens their motivation to attend. The number of voting members is 20, but this makes it necessary to have 11 members present to have a quorum. Since some members have to travel from Flagstaff or Tucson to attend meetings, obtaining a quorum is difficult. Having an odd number of members, would lessen that difficulty slightly.

5. The extent to which the Council has encouraged input from the public before adopting its rules and the extent to which it has informed the public as to its actions and their expected impact on the public

The Governor's Council on Arthritis and Musculo-skeletal Diseases has consistently given timely notice of Council meetings and agendas. It has, through its diverse membership, communicated information concerning current and upcoming issues to local chapters of the Arthritis Foundation and to public and private organizations concerned with all forms of arthritis. Information has also been shared with other Governor's Councils concerning public presentations on arthritis which have broad public interest and on public forums on rehabilitation. Members of the public frequently attend Council meetings as observers and are given the opportunity to make comments, raise issues or to give suggestions to the Council.

The Governor's Council on Arthritis and Musculoskeletal Diseases is seeking to play a more active role in the collection, synthesis and dissemination of national research data so that it can be applied in a timely fashion to the problems and needs of persons with arthritis or related diseases in Arizona

6. The extent to which the Council has been able to investigate and resolve complaints that are within its jurisdiction

As the Governor's Council has become aware of specific and individual problems of persons with arthritis or musculoskeletal diseases or of complaints from their families, it has either referred the person to an appropriate office or agency, such as the Client Advocacy Program, or has forwarded the content of the complaint to an appropriate level of the organization involved. This Governor's Council tends to concern itself more with ongoing, recurrent issues and problems that affect persons who are or will be suffering the ravages of arthritis and arthritis-related diseases. The Governor's Council is a constant advocate for informing and educating the public on means of resolving difficulties of communication with their private physicians, HMO's, clinics, hospitals and Medicare concerning the availability of services, medication issues, and, especially, the issues of prevention or treatment of secondary and tertiary sequellae, such as joint deformity, decrease or loss of function, depression, drug toxicity, kidney failure, and cardiac problems. According to Dr. Ted Pincus at Vanderbilt University, persons with arthritis, particularly those with juvenile arthritis or rheumatoid arthritis, tend to have a ten to fifteen years earlier mortality than the general population. Unfortunately, these victims are unable to register complaints.

7. The extent to which the attorney general or any other applicable agency of state government has the authority to prosecute actions under the enabling legislation

As a public body established by the Governor and confirmed by the Arizona legislature, the Governor's Council is required to adhere to the requirements set forth in the enabling legislation and also with the Open Meeting Law (Laws 1962, chapter 138, item 1). Council officials deliberately violating the Open Meeting Laws are , under A.R.S. 38-431.07, liable to a superior court fine not to exceed five hundred dollars.

8. The extent to which the Council has addressed deficiencies in its enabling statutes which prevent it from fulfilling their statutory mandate

In the past the Council has requested changes in the statute which would allow ex-officio members the privilege of voting, since the actions and decisions of the Council are of an advisory nature and are not likely to directly influence agencies represented by these persons. The Council has also sought to affect the requirements of a quorum, which is presently one more than half of the voting membership. An odd number of voting members would make it easier to achieve the present quorum requirement of 51% of voting members.

9. The extent to which changes are necessary in the laws of the Council to adequately comply with the factors listed in this subsection.

The Council presently receives no financial support other than per diem and travel expenses for its members to attend meetings. The occasional part-time services of a Council staff member and secretary are provided by the Rehabilitation Services Administration of the Department of Economic Security. A formal budget with funding would increase the Council's discretionary ability to carry out its mission and objectives.

As stated above, having a less stringent quorum requirement and allowing ex-officio members the right to vote could improve the effectiveness of the Council.

10. The extent to which the termination of the Council would significantly harm the public health, safety or welfare

While a number of public, non-profit, and private agencies serve certain specific needs of persons with arthritis or musculoskeletal diseases, no official body other than the Governor's Council on Arthritis and Musculoskeletal Diseases exists to oversee the overall problems, needs and welfare of this sizeable population. The elimination of this Governor's Council would have the effect of reducing the communication, cooperation and collaboration efforts among the numerous organizations serving the culturally diverse and geographically separated, even at times isolated, unwilling members of the arthritis and musculoskeletal diseased community. That same ever-increasing community would lose the services of a staunch advocate of their rights and of the varied services they require in the areas of research, prevention, education, treatment and rehabilitation.

11. The extent to which the level of regulation exercised by the Council is appropriate and whether less or more stringent levels of regulation would be appropriate

As an advisory body this Council has no power to enforce its decisions or recommendations. It even lacks the funding to authorize expenditures or to hire services of consultants. In the past it has exercised influence on the practices and procedures of organizations with which it deals, and has focused largely on the education of the public and health professionals on the problems, issues and developments in the field of arthritis and musculoskeletal diseases.

12. The extent to which the Council has used private contractors in the performance of its duties and how effective use of private contractors could be accomplished

The Council has successfully procured volunteer services of health professionals as presenters at regional conferences and for the collection and dissemination of research data. It has also obtained the free use of facilities and other resources from organizations with which it regularly interacts. However, the ability to contract persons to collect, analyze, and synthesize research, or develop informative brochures, or to make public and/or professional presentations on related health and rehabilitation issues would enlarge the Council's impact throughout the state. The Council would utilize the advice and recommendations of the professional health community in the selection of qualified persons to carry out vital functions that are presently not being performed in Arizona. To the extent possible, those health organizations would share responsibility for designing, implementing and funding these useful projects.

I hope that these responses meet your needs. If not, please call me at (520) 321-0692.

Sincerely,



Gail Kershner Riggs
Council chairperson
Attachments

Copies of minutes of meeting for SFY 1994 through 1996
Annual report

ARIZONA COUNCIL ON ARTHRITIS AND MUSCULOSKELETAL DISEASES

July 26, 1996

To Senator Ann Day and Sue Gerard
Co-chairs, Health Committee of Reference
Arizona Legislature

RESPONSES TO QUESTIONNAIRE:

1. Describe the role and function of the Council including major activities/projects, accomplishments and obstacles to success.

"The Governor's Council on Arthritis and Musculoskeletal Diseases was established by legislative statute to address the problem of arthritis and musculoskeletal diseases by bringing together organizations and individuals with a knowledge and basic interest in this area in order to develop recommendations the state may adopt to help meet the needs of victims of these diseases"(Laws 1987, ch. 258, 1 and 5).

The duties and responsibilities of the Council include:

- to advise and assist the Governor, the Legislature, and all State Agencies providing services to persons suffering from arthritis and/or musculoskeletal diseases (such as RSA and the AZ Dept. of Health);
- to submit an annual report, and conduct an annual statewide conference to address issues and exchange information;
- to review and make recommendations or plans and strategies for meeting the needs of persons with arthritis and/or musculoskeletal diseases;
- in cooperation with all related organizations, to conduct programs of professional and public education;
- to serve as a repository of information on arthritis and musculoskeletal diseases, referral procedures, and demographics of these diseases;
- to monitor programs and services for persons with arthritis and musculoskeletal diseases to encourage efficient and coordinated use of resources.

In carrying out its responsibilities the Council, either as a whole or through its committees or individual members, has engaged in the following activities:

- communicating with legislative committees and individual representatives or senators involved in health and other issues relating to the needs and interests of persons with arthritis and related musculoskeletal diseases;

-communicating with program administrators of the Dept. of Economic Security and the Department of Health concerning specific policies and procedures affecting their clients with arthritis. Specifically, the Council advised the Rehabilitation Services Administration on its Order of Selection and advised the Dept. of Health Services on continuing its disability prevention project. The Council also advocated to the legislature for special funding for that project;

-communication and cooperation with the Phoenix and Tucson chapters of the Arthritis Foundation and its national office, the Harrington Arthritis Research Center, the University of Arizona Arthritis Center, private arthritis specialists and regional medical centers. Their collaborative efforts include public and professional educational presentations on important issues in the prevention, treatment and rehabilitation of diseases such as rheumatoid arthritis, lupus and multiple myeloma in a number of cities throughout the state; Significant research findings have also been disseminated by means of these public presentations and by direct mailings to persons and organizations with interest or involvement in providing services to persons with arthritis and musculoskeletal diseases;

-one member of the Arthritis Council participates on the Disability Prevention Advisory Council; another serves on the Governor's Council on Blindness and Visual Impairment. This cross-representation helps facilitate communication among Councils with common interests.

- as a result of the Council's collaborative efforts with other councils and organizations in demanding improved access to information for persons with disabilities, the Disability Hotline of Arizona and a 24-hour, statewide information and referral system on rehabilitation services were established.

In seeking to carry out its mission and objectives, a major obstacle is the lack of a budget which would allow the Council the discretion to make needed purchases, hire consultants for special projects, to purchase books and documents and to rent or purchase equipment, supplies or services required for special projects. For instance, in order to "serve as a repository of information on arthritis...", one of the mandated duties of the Council, space, cabinets or book shelves, means of purchasing or publishing and reproducing documents, means of sending and receiving information and documents, such as phone, fax, and mail services would be required. None of these can presently be obtained by the Council. Such necessary items and services should be able to be planned and provided for in an approved budget with money provided by the legislature or designated state agency.

Otherwise, mandated duties that cannot be carried out in the absence of adequate financial assistance should be deleted from the wording of the legislation.

Q. 2. Provide financial data such as number of full-time employees, expenditures and revenues and fee structure.

The only funding that the Council on Arthritis and Musculoskeletal Diseases receives is for travel and per diem expenses for its members and staff to travel to official Council meetings or in the performance of directly related Council activities. The Council staff and secretary are both provided by Rehabilitation Services Administration of DES. The administrative staff person (or liaison) spends about 10% of his time on assisting this Council; the clerical staff person spends about 5% of her time on Council affairs. Thus about \$3800 is spent on staff salaries. Another \$470 covers employee related expenses. The average annual cost of transportation for Council members is \$1200; Hotel accomodations for Council related trips is \$305. Per diem expenses is \$184. Thus R.S.A. pays about \$5959.00 per year to support Council activities.

The Council has utilized donated space and services of community organizations in carrying out its responsibilities.

Q.3. Provide information regarding Council composition including number of members, number of public members and method of appointment

In compliance with 41-971, the Council consists of the following members, all of whom are appointed by the Governor:

- nine members who are afflicted with arthritis or are parents or guardians of arthritis victims; Six of these members are selected from a list of individuals recommended by a statewide private nonprofit organization (the Arthritis Foundation);

- five members who represent the professional health community in rheumatology;

- two members from the general community and who have a knowledge of and interest in the subject of arthritis and musculoskeletal diseases;

- one (advisory) member who represents a statewide private nonprofit agency which provides services to persons with arthritis and musculoskeletal diseases;

- one (advisory) member representing a private nonprofit research center which conducts biomedical research or bioengineering research in arthritis and musculoskeletal diseases;

- the Director of DES or her designee (advisory)

- the Director of the Dept. of Health Services or his designee (advisory)

- the chairman of rheumatology at the U.of A research center (advisory)

Thus the Council consists of twenty-one members, including sixteen voting members. The Council solicits recommendations from its member individuals and organizations and from the public at large. The Council votes on which to select, and forwards their nominations to the Governor's Office of Boards and Commissions for his consideration. All appointments are made at the discretion of the Governor.

Attached is a current list of members indicating the category each represents and the date his/her term will expire.

Respectfully submitted by

Gail Kershner Riggs

Gail Kershner Riggs, MA, CHES
Council chairperson

MINUTES OF COMMITTEE OF REFERENCE MEETING

(Section D)

ARIZONA STATE LEGISLATURE

**SENATE AND HOUSE HEALTH COMMITTEES OF REFERENCE
SUNSET REVIEWS OF THE**

BOARD OF RESPIRATORY CARE EXAMINERS

**ARIZONA GOVERNOR'S COUNCIL ON ARTHRITIS
& MUSCULOSKELETAL DISEASES**

**JOINT LEGISLATIVE COMMITTEE FOR THE ARIZONA HEALTH CARE
COST CONTAINMENT SYSTEM**

Minutes of the Meeting
Wednesday, October 23, 1996
9:00 a.m., Senate Hearing Room 2

MEMBERS PRESENT

Senator Day, Co-chairman
Representative Gerard, Co-chairman
Senator Brewer
Senator Petersen
Representative Aldridge
Representative Horton
Representative Foster

MEMBERS EXCUSED

Senator Kennedy
Senator Henderson
Representative Preble

STAFF

Kitty Boots, Senate Analyst
Lisa Block, House Analyst

Co-chairman Day convened the meeting at 9:10 a.m. and the attendance was noted. Senator Day explained the purpose of the sunset hearings is to review the purpose and function of each entity to determine whether they should be continued, revised, consolidated or terminated.

BOARD OF RESPIRATORY CARE EXAMINERS

Mary Hauf Martin, Executive Director, Board of Respiratory Care Examiners, explained the Board was created in 1990 and oversees Respiratory Care Practitioners (RCPs) who provide services in hospital settings and increasingly in alternative settings such as skilled nursing facilities and private homes. She explained the Board must insure an RCP cares for patients safely and effectively. Ms. Martin explained RCPs work with health care teams to insure quality patient care and cost containment in a continually changing environment.

In response to Senator Day's request to hear examples of ways RCPs are adapting to a changing environment, Ms. Martin explained RCPs at St. Joseph's Hospital in Phoenix are now integrated into all departments, rather than being centralized in a department of their own, and are involved in total patient care, e.g. helping to move a patient as well as

performing respiratory care. She also indicated that since patients are leaving the hospital sooner after medical procedures, RCPs have gone into homes to train patients on the use of respiratory equipment.

Senator Day asked if Ms. Martin sees managed health care as supporting an adequate number of home visits and extended care by RCPs. Ms. Martin indicated that managed care has worked collaboratively to provide necessary services.

In response to Senator Day's request to know if Ms. Martin sees services being cut back by managed care, Ms. Martin indicated that she did not feel qualified to respond. She emphasized there is an effort on the part of the respiratory care industry to answer the need that exists.

Ms. Martin explained the Board is made up of three practitioners, one medical doctor, one hospital administrator and two members of the public, emphasizing that the majority of the Board is not made up of practitioners and takes its responsibility to protect the public health very seriously. She noted that Board meetings are very well attended by health care facility representatives and interested licensees.

Ms. Martin further explained disciplinary procedures are reviewed to assure that people are being treated fairly and equally. She indicated an independent study performed by the Auditor General reveals the Board compares favorably to similar boards. Ms. Martin indicated it has taken the Board about 60 days to process a complaint from beginning to resolution, that 26 percent of complaints have resulted in disciplinary action and that 34 percent have resulted in a warning letter of concern in the past year.

In response to Representative Aldridge's request to know what qualifies a person to be an RCP, Ms. Martin explained an applicant for a license must be a high school graduate and graduate from an accredited respiratory therapy training program. Once training is completed, an application for a license may be filed and is granted within 24 hours at which time the applicant may seek on-the-job training under the supervision of a doctor or another licensee until he or she can pass a national exam called the CRTT. Ms. Martin indicated that once the applicant passes the CRTT, he or she is eligible for a permanent license.

In response to Representative Aldridge's request to know how long the training program is, Ms. Martin explained it lasts approximately a year, which is longer now than in the recent past, due to enhanced education in using high-technology equipment.

Representative Horton referred to page five of the preliminary sunset report (filed with original minutes) and asked for the reason behind the fluctuation in the number of license denials and total number of complaints charted there. Ms. Martin explained a backlog in

**HEALTH COMMITTEES OF
REFERENCE SUNSET REVIEWS**

October 23, 1996

Page 3

processing complaints occurred last year, but was alleviated once a staff position was authorized by the Legislature.

In response to Senator Day's inquiry, Ms. Martin acknowledged that every year there has been a gradual increase in the number of complaints. She explained that the biggest problem behind complaints is substance abuse by practitioners.

Representative Horton asked if criteria used for foreign applicants are the same for citizens of the United States. She asked how the Board determines how the foreign applicants have the same standardized training.

Ms. Martin explained that Canada, where the majority of foreign applicants are from, has a very rigorous training program which is accepted as an equivalent by a national organization for respiratory care examiners.

In response to Representative Horton's wish to know what legislation the Board would be pursuing next session, Ms. Martin indicated it would be developing technical legislation to clarify language only.

In response to Senator Brewer's request to know if the Board certifies the respiratory care training facilities that applicants attend, Ms. Martin explained a national accreditation body, consisting of four groups of practitioners, determines what constitutes an approved program. She further explained the Board assures that applicants have attended an American Medical Association-approved program.

In response to Senator Brewer's further inquiry about where applicants go to school, Ms. Martin related the majority are attending community colleges to obtain their training.

Ms. Martin confirmed Senator Brewer's observation there are no independent, privately-owned respiratory therapy colleges in Arizona.

Representative Horton asked what the Board does to screen applicants for drug abuse. Ms. Martin explained this is a collaborative effort between the Board and care facilities that employ RCPs. She indicated the Board does not have the ability to perform criminal background checks on every applicant, however does ask them specific questions about their backgrounds and requires they submit a sworn statement that everything they have told the Board is true and factual. Ms. Martin additionally noted that facilities routinely perform preemployment drug screenings and also have the ability to perform "for cause" drug screenings when necessary.

David Feuerherd, Program Director, American Lung Association, expressed his support for continuing the Board in response to Senator Day's inquiry.

John Coleman, RCP and Member of the Board, explained the process whereby a patient is transferred from a hospital setting to home care using skilled, licensed RCPs.

In reference to Senator Day's concern about benefits being cut back in the managed health care environment, Mr. Coleman asserted the issue requires that home care companies adapt their contracts with managed care health plans. He explained that typically, depending on the patient's level of acuity, they may be seen once a week, once every six weeks or more often in the case of ventilator patients.

Senator Day indicated that according to information she receives from constituents, managed care cuts back on benefits to home care facilities and is not always providing services that patients need.

Representative Gerard asked if complaints from patients received by the Board concern quality of care. Mr. Coleman indicated the Board does not receive these types of complaints, as these are directed to the home care company or the insurance provider.

Representative Gerard asked if employers of RCPs have an obligation to report unprofessional conduct or incompetency to the Board and Mr. Coleman responded affirmatively.

Representative Gerard indicated she has never received a complaint about the Board, acknowledged the need to license RCPs and recommended continuing the Board for ten years.

Senator Brewer asked if RCPs bill directly or through the organization they work for. Mr. Coleman explained this depends upon the environment in which the RCP is working, noting that at this point in time, there is no set fee the RCP charges to go into a home care setting. He explained that compensation for the RCPs is built into the charge for equipment that is reimbursed. In hospital settings, Mr. Coleman explained, payment is disbursed through the hospital, not billed to the patient directly.

In response to Senator Brewer's reference to oxygen suppliers' problem with needing to hire RCPs to deliver their product, Mr. Coleman stressed this is a way to protect the public. He emphasized that it is perfectly appropriate and desirable to have a licensed practitioner teaching patients about the use of prescription drugs and oxygen equipment in their homes.

Representative Gerard moved that the Committee of Reference recommend to the full body the continuation of the Board of Respiratory Care Examiners for ten years. The motion CARRIED by a voice vote.

**ARIZONA GOVERNOR'S COUNCIL ON ARTHRITIS AND MUSCULOSKELETAL
DISEASES**

Pami Kowal, Member, Governor's Council on Arthritis and Musculoskeletal Diseases, explained that Gail Riggs, Council Chairperson, was only notified of the meeting yesterday and could not attend with such short notice.

Senator Day acknowledged the notice was late due to a lag in communication.

In response to Senator Day's inquiry about Ms. Kowal's understanding of the Council budget matters, Ms. Kowal indicated the budget is small, has not changed and the Council does not anticipate the need to request an increase.

Bob Gilligan, Legislative Liaison, Arizona Department of Economic Security (DES), explained DES provides a staff person part-time to perform Council duties as well as many other duties for DES. He indicated DES provided a little more than \$600 this year to the Council to reimburse members for travel to four meetings, and approximately \$400 the year before for the same purpose.

After some discussion it was determined that per diem expenses were compensated at the rate of \$600 for an entire year, hotel and transportation expenses at \$1,200, and that 5 percent of DES clerical staff committed to the Council amounted to \$3,800, for a total cost of approximately \$6,000 per year.

Senator Day questioned the purpose of the Council in view of the fact that the Arthritis Foundation exists for much the same purpose.

Ms. Kowal acknowledged the Foundation serves its purpose very well, but explained the Council functions in addition to the Foundation in pursuing legislative activities and community outreach and education.

In response to Senator Day's request to know how the Council specifically serves an education function, Ms. Kowal indicated that the Council holds public forums in outlying areas to educate people about arthritis and the importance of early detection and treatment.

Senator Day asked if the educational activities are conducted by volunteers and Ms. Kowal confirmed that everything the Council does is conducted on a volunteer basis.

Representative Gerard read from the Executive Summary of the preliminary sunset report (filed with original minutes) that the Council's purpose is to "develop recommendations the

State may adopt to help victims of these diseases," and asked if anything specific has been done other than to call the congressional delegation, which is noted in the Council's response.

Ms. Kowal responded that the Council has been actively involved in assuring vocational rehabilitation is continually supported and has applied for funding for particular research grants.

In response to Senator Day's request to know how successful the Council has been in obtaining a research grant, Ms. Kowal expressed her understanding the Council has obtained one research grant but it has not moved forward for some reason.

In response to Representative Gerard's inquiry, Ms. Kowal acknowledged the Council would not be conducting research, only applying for grants and providing support. Representative Gerard suggested the University of Arizona Medical Center could apply for such a grant as well. Ms. Kowal acknowledged this and noted the Foundation also applies for grants.

Representative Gerard asked if the Council is a pass-through agency for receiving any type of federal monies and Ms. Kowal expressed her understanding it is not.

Representative Gerard asserted there is no need for the Council and that its function should be handled in the private sector.

Representative Aldridge suggested the work of the Council should be coordinated with the Arthritis Foundation.

Ms. Kowal emphasized that the Council is a group of close-knit professionals who want to provide additional support to the Foundation, especially in the legislative area to see that arthritis is eradicated and people educated about it. She emphasized that the Council members would want to continue in their efforts even without funding.

Representative Aldridge asserted he does not see any concrete results provided by the Council.

Ms. Kowal reviewed goals and objectives for the following year including setting up an informal arthritis registry as an outreach, especially to outlying areas, to get people properly channeled to see a specialist as soon as possible after diagnosis. She emphasized that the Council is composed of many committed people with outstanding ideas and has only had a chance to hold one meeting out of six planned so far this year.

**HEALTH COMMITTEES OF
REFERENCE SUNSET REVIEWS**

**October 23, 1996
Page 7**

Senator Day acknowledged Ms. Kowal's dedication and that of Council members, and suggested they may enjoy the status of being appointed by the Governor. She suggested that if members are dedicated enough, they can pursue their goals independently.

Representative Horton read a recommendation from the preliminary sunset report stating the "Arizona legislature should increase funding" and read from goals and objectives, noting the Council asks for a "full match of State funding to pull down maximum federal funding for DES."

Senator Day related that in a recent conversation, Ms. Riggs indicated the Council expects no additional funding from DES and is working with the Foundation to obtain matching funds.

Ms. Kowal urged the Committee to allow the new Council members an opportunity to show the State what it can do.

In response to Representative Foster's inquiry about how much the Council collaborates with the Foundation, Ms. Kowal acknowledged it collaborates functions a great deal and noted some members of the Board are also members of the Foundation.

In response to Representative Horton's suggestion that the Council function as an advisory committee to the Foundation, Ms. Kowal explained the Foundation, based in Atlanta, Georgia, already has quite a few committees in place and questioned whether a particular state's Governor's Council could become an advisory committee, suggesting this would probably taking quite a bit of convincing.

Representative Gerard moved that the Committee of Reference recommend to the full body the termination of the Arizona Governor's Council on Arthritis and Musculoskeletal Diseases. The motion CARRIED by a voice vote.

Senator Brewer voted against the recommendation, asserting that not enough information was received to warrant termination and suggested the Council should be continued for one year so it could be clearly established whether money should come out of DES to fund it or not.

Representative Horton voted against the recommendation because she had remaining questions and felt uncomfortable about terminating the Council when Ms. Riggs could not be present to respond.

**JOINT LEGISLATIVE COMMITTEE FOR THE ARIZONA HEALTH CARE COST
CONTAINMENT SYSTEM (AHCCCS)**

Kitty Boots, Senate Research Analyst, explained the Committee charge is to conduct negotiations relating to all agreements with the federal government and the State concerning Title XIX programs, to review and make recommendations concerning all proposals for additions or modifications to populations covered or services provided by AHCCCS or any state agency providing services to populations eligible under Title XIX. She additionally explained the Committee is charged with monitoring the implementation of additional fees and modifications including the review of preadmission screening instruments, the eligibility and enrollment system and the service delivery system. Ms. Boots indicated the Committee is also to review the implementation of the hospital payment methodology and must review and approve all hospital rate changes before the implementation of changes in hospital rates.

Ms. Boots indicated the Committee has met six to seven times over the past six years to address issues, including those listed on page two of the preliminary sunset report (filed with original minutes). She noted the Committee is required by statute to meet at least four times per year and this charge has not been met.

Ms. Boots noted there are ongoing projects the Committee may choose to review, including reviewing and holding public testimony on the rules proposals for the new AHCCCS reimbursement pilot project, reviewing the impact of the new federal welfare reform bill and reviewing the impact of pending initiatives should they pass in the November election.

Senator Day stressed the need to continue this Committee, recommended doing so for ten years and recommended changing the statutory requirement of meeting four times a year to "meeting at the discretion of the co-chairmen."

Representative Horton expressed her concern the Committee does not meet frequently enough as it is and needs to meet more often.

Representative Gerard asserted the Committee is not necessary and recommended using the Joint Legislative Health Committees of Reference to treat AHCCCS issues. She acknowledged there was a need for the oversight when AHCCCS first started up and received its federal waiver, but the need has run its course.

Representative Aldridge agreed there is no longer a need for the Committee and Senator Day withdrew her previous recommendation.

**HEALTH COMMITTEES OF
REFERENCE SUNSET REVIEWS**

**October 23, 1996
Page 9**

Representative Gerard moved the Committee of Reference recommend to the full body the termination of the Joint Legislative Oversight Committee on the Arizona Health Care Cost Containment System (AHCCCS), expanding the scope of the Joint Legislative Health Committees of Reference to encompass dealing with questions concerning AHCCCS. The motion CARRIED by a voice vote.

Without objection the meeting was adjourned at 10:30 a.m.

Respectfully submitted,



Alice Kloppel,
Committee Secretary

(Tape and attachments on file in the Office of the Senate Secretary)

ATTENDANCE LIST

(Section E)



STATE OF ARIZONA
EXECUTIVE OFFICE

FIFE SYMINGTON
Governor

ADVISORY COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES
A.R.S. 41-971 / 972

The Honorable Carolyn Allen
Arizona House of Representatives
1700 W. Washington
Phoenix, AZ 85007

Lee Brest
1926 E. Granito Vista
Tucson, AZ 85713

Paul H. Caldron, D.O.
3330 N. Second Street
Phoenix, AZ 85012

Carol Chamberlain
777 E. Missouri, #119
Phoenix, AZ 85014

Michelle Cornett
4737 N. Geronimo
Tucson, AZ 85704

Dr. Timothy Flood
1400 W. Washington
Phoenix, AZ 85007

Oscar Gluck, M.D.
AZ Rheumatology Center
6036 North 19 Ave, #312
Phoenix, AZ 85015

Member w/Arthritis
542-4225 (O)
Term Expires: 1/18/99
Replaced: Willard Page

Member w/Arthritis
624-1375 (H)
Term Expires: 1/18/99
Replaced: Ken Jacuzzi

Rheumatologist
759-0716 (H) / 234-3434 (O)
Term Expires: 1/19/98
Replaced: Reappointment

**Advisory Member-Arthritis
Foundation Representative**
264-7679 (H)

Public Member
293-2843 (H) / 626-6041(O)
Term Expires: 1/18/99
Replaced: Reappointment

**Advisory Member - Dept of Health
Services Representative**
230-5881 (O)

Professional/Rheumatologist
246-1964 (O)
Term Expires: 1/19/98
Replaced: Leanna Crosby

**ARTHRITIS & MUSCULOSKELETAL ADV COUNCIL
PAGE TWO**

Cele Kennedy
505 W. Solano Drive
Phoenix, AZ 85013

Member w/Arthritis
277-3713 (H)
Term Expires: 1/20/97
Replaced: Reappointment

Pami Kowal
7921 E. Willetta Street
Scottsdale, AZ 85257

Member w/Arthritis
946-6172 (H)
Term Expires: 1/18/99
Replaced: Ed Lynch

Dodie M. Londen
33 Biltmore Estates
Phoenix, AZ 85016

Member w/Arthritis
956-7971 (H) / 957-7770 (O)
Term Expires: 1/19/98
Replaced: Vacant Position

Barbara Matia
4829 East Beryl Avenue
Scottsdale, AZ 85253

Member w/Arthritis
951-2028 (H)
Term Expires: 1/19/98
Replaced: Reappointment

Dr. Francis Nardella
10599 N. Tatum Blvd, #F-150
Paradise Valley, AZ 85253

Professional Community
443-8400 (O)
Term Expired: 1/15/96
Replaced: Dr. Linda Karl

Lori Pearlmutter – Chair
Post Office Box 23803
Flagstaff, AZ 86002

Professional Community
526-5555, X-6613 (H) / 773-2125 (O)
Term Expires: 1/20/97
Replaced: Reappointment

Gail Kershner Riggs
3011 N. Palomino Park Loop
Tucson, AZ 85712

Member w/Arthritis
321-0692 (H) / 6266854 (O)
Term Expires: 1/19/98
Replaced: Reappointment

Dr. Barry Sauer
1800 E. Van Buren
Phoenix, AZ 85006

Advisory Member -
Harrington Research Center
254-0377 (O)

**ADVISORY COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES
PAGE THREE**

Noreen Shcolnik
1789 W. Jefferson, #930A
Phoenix, AZ 85007

**Advisory Member-Dept of
Economic Security Rep**
542-3332 (O)

Dr. David Wayne Smith
c/o Arthritis Foundation
6464 E. Grant
Tucson, AZ 85715

Professional Member
290-9090 (O) / 529-0155 (H)
Term Expires: 1/20/97
621-9118 - FAX
Replaced: Reappointment

Dr. John Szivek
Arizona Health Sciences Center
1501 N. Campbell
Tucson, AZ 85724-5064

Public Member
626-6094 (O)
Term Expires: 1/19/98
Replaced: Linda Brickman

Carol Wilson
8815 East Snyder
Tucson, AZ 85747

Parent of Child w/Arthritis
290-9090 (H)
Term Expires: 1/19/98
Replaced: Kathleen Acciaioli

Kelly Wyland
3935 Tanyuri Drive
Tucson, AZ 85715

Person w/Arthritis
722-0940 (H)
Term Expire: 1/18/99
Replaced: Beverly Bulla

David E. Yocum, M.D.
Health Sciences Ctr, Rm 6409
1501 N. Campbell Avenue
Tucson, AZ 85724

**Adv Member-Rheumatology
Dept - Univ of AZ**
626-6041 (O)
Replaced: Dr. Eric Gall

Vincent Kelly
DES-RSA
1789 W. Jefferson, 930A
Phoenix, AZ 85007

Council Liaison
542-2595 (O)

GOVERNOR'S COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES
Minutes
November 9, 1994

Members Present

Paul Caldron
Carol Chamberlain
Michelle Cornett
Cele Kennedy
Barbara Matia
Francis Nardella
Lori Pearlmutter
Gail Kershner Riggs
David Wayne Smith

Members Absent

Kathleen Acciaioli
Linda Brickman
Beverly Carol Bulla
Leanna Crosby
Tim Flood
Eric Gall
Eddie Lynch
Willard Page

Guests

Gail Ebeltoft, University of Arizona
Denise Hanton, Occupational Therapist, Flagstaff
Linda Olson, RSA Planning & Evaluation Manager
Richard Porter, AZ Department of Health Services, Phoenix
David Yocum, University of Arizona

Staff

David Beard
Grace VanWinkle

The meeting was convened at 12:20 p.m. by Lori Pearlmutter, Chairperson.

Introductions

Members and guests introduced themselves.

Approval of Minutes

A motion was made by David Wayne Smith and seconded by Cele Kennedy to approve the August 16, 1994 minutes. The motion carried by unanimous voice vote.

Old Business

Lori Pearlmutter reported that she has received a letter from the Arizona Department of Health Services in response to her request for \$5,000 in grant money. The grant request was denied, but the Department of Health Services offered to provide technical assistance in seeking funding from the Arizona Disease Control Research Commission in the future. (A copy of this letter is attached.)

Dr. David Smith reported on the "Unfunded Federal Mandate" issue that was discussed and voted on at the last meeting. Dr Smith reported that it is among a number of unfunded federal mandate issues that will be prioritized by the Governor's office and the legislature to take forward in a court case. Dr. Smith will report on the timetable of this lawsuit at the next Council meeting.

Dr. Yocum reported on a population cluster in Nogales, Arizona who appear to have a high rate of lupus and multiple myoma in a small area only two or three blocks from the Mexican border. This area is in close proximity to an old landfill/garbage dump. Additionally, investigation in an area south of Tucson showed ground water contamination which also caused toxic exposure. He feels there is a possible strong association with these locations to lupus, cancer and infectious diseases that needs to be examined. Dr. Yocum suggested that the Arthritis Council be spokespeople for those affected by these problems and that the Council needs to take a pro-active role regarding this issue. He suggested the Council obtain more information, look at ways to intervene as an educated advocate, and report on these issues to the Governor. Discussion followed. Dr. Smith asked that the next Council meeting be held in the Nogales or Tucson area, and that locally involved professionals be invited to make presentations at the meeting to further investigate this issue. Larry Clark, Bridgett Walsh, Leslie Boyer and Cecelia Campillo were suggested as presenters. Dr. Yocum will set up an agenda, and the Council will meet at 4:00 p.m. on February 8, 1995 at the Medical School in Tucson. Further details will be sent out with next meeting notice.

Dr. Smith inquired about Ms. Pearlmutter's letter to the federal RSA and to the Arthritis Foundation in Atlanta regarding Order of Selection in other states. Since she has not received a reply, he asked that she re-send the letter to Ms. Mary Long at the Arthritis Foundation and to Commissioner Fred Schroeder at RSA.

New Business

Barbara Matia reported that as a result of their meeting in Washington in 1982, Senator DeConcini has now introduced a bill to establish Cooperative Units of Research in Infectious Diseases. (Copy attached.) The Senator has made a commitment to her that it is his No. 1 priority to see this bill is passed. She enlisted the support of the Council to get this important bill passed. Ms. Matia will keep the Council informed on this issue. Dr. Smith recommended that Senator Orin Hatch of Utah re-introduce the bill. Discussion followed. It was suggested that a request for support (and an example of a letter of support to a Congressman) be included in the Arthritis Foundation newsletter along with an article about Ms. Matia's personal experience with arthritis over the past 20 years.

Ms. Matia also distributed copies of her letter regarding Governor's Arthritis Council membership. She requested the Council's help in identifying new member prospects who care deeply about arthritis. David Beard advised that we need letters of resignation from current members who do not attend and no longer care to be on the Council. Ms. Matia asked that the Council redefine the role of the Governor's Council and define the role of individual members. Lori stressed the Council's advocacy role. Cele Kennedy suggested memoing the Governor through a staff member about current Council issues. Dr. Yocum also suggested investigating the possibility of newspaper and other public relations coverage.

The meeting was adjourned at 2:20 p.m.



GOVERNOR'S COUNCIL ON ARTHRITIS AND MUSCULOSKELETAL DISEASES

State of Arizona

June 2, 1994

Mr. Howard Moses
Acting Commissioner
Rehabilitation Services Administration
U.S. Department of Education
400 Maryland Avenue S.W.
Switzer Building, #3028
Washington, D.C. 20202-2531

Dear Mr. Moses:

I am writing as Chair of the Governor's Council on Arthritis and Musculoskeletal Diseases which represents over a half million people in Arizona with Arthritis, to draw your attention to amendments in the Rehabilitation Act of 1973. These amendments will cause hardships for the Arizona Department of Economic Security, Rehabilitation Services Administration (RSA) and its clientele, the disabled citizens of Arizona.

The amendments now require states to provide vocational rehabilitation to all disabled individuals, unless RSA can prove they will not benefit. The amendments also require RSA to provide services to the most severely disabled, before others, if only limited funds are available. This requirement is the most troublesome.

In states like Arizona, only limited funds are available. RSA receives state funding and matching funds from the federal government. Thus, RSA currently serves only the severely disabled.

The amendment needs to be changed. Priority should be given to serving the disabled who are most likely to benefit from vocational rehabilitation and return to work, whether they are severely disabled or not. Numerous state-of-the-art systems exist for selecting those disabled persons for whom vocational rehabilitation is likely to result in success; that is, gainful employment. The medical literature clearly indicates that vocational rehabilitation for severely disabled persons cannot produce success stories for all of them. Thus, the amendment's priority for providing vocational rehabilitation to the severely disabled should be repealed and replaced with a requirement to evaluate disabled persons for their likelihood for success.

Howard Moses
Acting Commissioner
June 2, 1994
Page 2

A recent report by the Center for Disease Control has found the nationwide prevalence of arthritis to be over 20%, with many of those reporting disability. Many of these people are not able to receive vocational rehabilitation through RSA because they do not fit into the category of severely disabled. We do know that these people are often the ones who will benefit most from rehabilitation in order to return to gainful employment.

I urge you to reconsider these amendments. It is imperative that we use our finances wisely to rehabilitate those most able to benefit and help them to return to work.

Sincerely,



Lori Pearlmutter
Chairperson

LP:NW:gv

c:
Governor Fife Symington
Roger J. Hodges
Linda Blessing
Mary Long



*Disease Prevention Services
Office of Chronic Disease Epidemiology
Office of Disability Prevention*

1400 W. Washington
Phoenix, Arizona 85007
(602) 542-7340
(602) 542-1753 FAX

PIFF SYMINGTON, GOVERNOR
JACK DILLENBERG, D.D.S., M.P.H.,
DIRECTOR

September 12, 1994

Lori Pearlmutter, P.T.
Clinical Supervisor, Therapy Services
Flagstaff Medical Center
1200 North Beaver Street
Flagstaff, Arizona 86001-3118

Dear Lori:

In response to your letter of May 31, 1994, the Office of Disability Prevention did request funding in our 1994-95 Continuation Application for a project to address the secondary conditions associated with arthritis. In our recent budget negotiations with the Centers for Disease Control and Prevention, that project was unable to be funded due to decreased levels of funding.

While we are unable to provide support for a project for the Governor's Council on Arthritis and Musculoskeletal Diseases, we would be willing to provide technical assistance to your Council if you are interested in seeking funding from the Arizona Disease Control Research Commission. The decision would need to be made quickly as the due date for the proposals is October 14, 1994.

For your review, we are enclosing a copy of: a) the CDC project guidelines that were used to develop the project design that was submitted with the Continuation Application; and b) the project description.

If you decide to proceed with the preparation of a response to the RFP from the Commission, contact the Commission at 542-1028 to request a copy of the RFP. After you have had an opportunity to review the material, please contact Dr. Pam Goslar or myself at 542-7340 if you have decided to proceed and would like technical assistance in the preparation of your response.

GOVERNOR'S COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES
Minutes
August 16, 1994

Members Present

Paul Caldron
Carol Chamberlain
Michelle Cornett
Cele Kennedy
Barbara Matia
Lori Pearlmutter
David Wayne Smith

Members Absent

Kathleen Acciaioli
Linda Brickman
Beverly Carol Bulla
Leanna Crosby
Tim Flood
Eric Gall
Eddie Lynch
Francis Nardella
Willard Page
Gail Kershner Riggs

Guests

Gail Ebeltoft
David Yocum

Staff

David Beard
Grace VanWinkle

The meeting was convened at 2:05 p.m., via a telephone conference call, by Lori Pearlmutter.

Introductions

Members and guests introduced themselves.

Approval of Minutes

A motion was made by Cele Kennedy and seconded by David Wayne Smith to approve the May 24, 1994 minutes. The motion carried by voice vote.

Old Business

MMWR Report - Since Dr. Flood could not attend this meeting, the discussion of the Morbidity and Mortality Weekly Report of 5/6/94 scheduled for today's meeting was tabled until the next meeting of the Council.

Lori Pearlmutter reported that she has sent a letter to Ann Tarpe, Department of Health Services, Disability Prevention Office, requesting \$5,000 to begin a pilot study for the Governor's Council on Arthritis and Musculoskeletal Diseases to determine accessibility to rehabilitation. The previous study determined that half a million people in Arizona have arthritis. Cele Kennedy commented that the same study was published, in part, in the latest issue of Arthritis Today. Carol Chamberlain volunteered to get copies of that study to Council members. Dr. Smith questioned the term "rehabilitation" in the study. Ms. Pearlmutter said that the Council is

write to members who have not been attending meetings and let them know that a letter of resignation is needed if they do not wish to continue serving on the Council. Discussion regarding potential new members followed. Recommendations from the Council were requested. Barbara Matia will let the Council know what categories of openings are available.

New Business

Council Meeting Dates - Lori Pearlmuter suggested the Council use teleconferencing twice a year and have two meetings where we meet face-to-face. Council members agreed. The next Governor's Council meeting will be Wednesday, November 9, 1994 at 12 noon at the Arthritis Foundation in Phoenix. It will be a luncheon meeting. It was decided that next year's meetings should be as follows:

1. Wednesday, February 8, 1995, 2:00 p.m., teleconference at the Arthritis Foundation in Phoenix.
2. Wednesday, May 10, 1995, at 2:00 p.m. in Casa Grande.
3. Wednesday, August 9, 1995, 2:00 p.m. a teleconference at the Arthritis Foundation in Phoenix.

The meeting was adjourned at 3:15 p.m.

Governor's Council on Arthritis and Musculoskeletal Diseases
Minutes
May 24, 1994

Members Present

Paul Caldron
Carol Chamberlain
Tim Flood
Cele Kennedy
Lori Pearlmutter

Absent

Kathleen Acciaioli
Linda Brickman
Beverly Carol Balla
Michelle Cornett
Leanna Crosby
Eric Gall
Eddie Lynch
Barbara Matia
Francis Nardella
Willard Page
Gail Kershner Riggs
Barry Sauer
David Wayne Smith

Staff

Nancy Washburn (for Noreen Shcolnik)

David Sears

The meeting was convened at 2:15 p.m. by Chairperson, Lori Pearlmutter. Introductions were made.

There were no corrections to the minutes. They will be voted on at the next meeting when there is a quorum.

Epidemiological Study

Tim gave copies to the members of an excerpt from the May issue of the Morbidity and Mortality Weekly Report which reproduced the results of a survey done by the Arizona Department of Health Services giving the most up to date statistics on persons with Arthritis in the State of Arizona, (1991-1992). He went over the highlights of the results, which included the number of estimated cases in Arizona, 567,000, and data on persons' activity limitations. These statistics were based on a survey of persons who self-reported and were doctor diagnosed. Copies of the report will go out with the minutes and agenda. Tim will also provide a cover letter for the report explaining some of the statistics.

Tim added that the Center for Disease Control (CDC) and the other states participating in this study will be presenting this information to two national meetings and the CDC will be proposing that other states do similar studies, thus Arizona being a leader in this effort.

Tim asked for members' feedback to the Center for Disease Control on how the committee would use this information. Lori responded that this data will be helpful in writing letters to legislators and others for support of issues and projects.

Tim then proposed that the council ask Arizona's Department of Health Services' Office of Disability Prevention for \$5,000 to fund a research project on Arthritis' secondary disabilities, specifically to explore and better define the causes of the secondary disabilities.

With input from research people at one or two of the universities, Lori will draft a letter, get Tim's input, and send.

RSA Update

Lori reviewed the history of and updated members about the two letters that the Council was going to send out regarding the 1992 Amendments and the Order of Selection. A letter asking the state legislature to support additional funding to RSA was not sent this year because specific amounts needed were not available from RSA.

Lori reported that she met with Roger Hodges today and that he is willing to work with the Arthritis Council on these projects and will be asking all councils to send support letters on critical RSA issues such as the Amendments and Order of Selection.

Lori then presented a draft letter regarding the Amendments and Order of Selection. Suggestions of changes to the letter were made and Lori will rewrite the letter and send. Per Carol's suggestion, she will find out from Roger the key people to send this letter. The target date to send will be June 3, 1994 and copies will be sent to the Governor, Roger Hodges, Linda Blessing, Director of DES, and Mary Long, Vice President of Government Affairs of the National Arthritis Foundation. In addition, Cele will take a copy to the Disability Prevention Council. She stressed the importance of changing the Order of Selection for people with Arthritis who rarely would be at the top of the priority list as it stands now.

Membership

Since Barbara has been unable to get a response from non-attending members, she will be sending a letter out after this meeting to them, giving them two weeks to respond. If there is no response, they will be taken off active membership. The committee concurred with this action, and Lori confirmed that the by-laws do state that three consecutive absences without good cause will be considered "intent to resign". There was a brief discussion on how new members are appointed.

The members then had a discussion about having meetings done through a conference call. Nancy will look into this option for the August meeting. In the meantime, however, Carol recommended that members be more responsive in their RSVPs to the meeting. If the meeting is not on conference call and the RSVPs indicate that the majority of the members will be coming from a particular area, that the meeting be held in that area, as long as the public meeting notice would be posted at least 48 hours before the meeting with the accurate meeting location.

Statute Change

Cele states she believes the Council's recommended changes to the statute passed in the legislature. Carol will call one of the legislators to verify, and if it did, copies will be sent to members.

New Business

Lori recommended that the annual report be changed to a biannual report. The one for '93-'94 would be submitted in November '94. Lori

asked Tim to write an update on the Epidemiological issues and she will do one on the RSA issues. She also asked members to think of other items that might be in the report.

Lori related that the Institute for Human Development at N.A.U. is asking for Council members' input on needs for assistive technology information or services because they are going to be writing an assistive technology grant. Lori took down suggestions and will share these with the Institute. Per Carol's suggestion, she will also ask them if a list of what assistive technology resources and equipment that has been provided is available and if it is, to send it to the Council.

Tim asked members for a source for public information on Lupus to have available to citizens attending an information sharing open house on June 17 & 18 in Nogales, where many people have contracted Lupus. Put on by the Department of Health Services and Department of Environmental Quality, this will be a time for them to meet with physicians to get information. Carol will provide him with printed materials and suggested a person to attend who can inform them as well.

Tim also added that since Arthritis has been asked to be added to the disabling conditions studied by Office of Disability Prevention, that this Council consider supporting a policy issue package by the Division of Disease Prevention asking for the state to fund this office, once its federal funding dries up in two years. The package will be given to the Director and then, if approved, would go to the Legislature for consideration.

Nancy informed the members of an RSA and ARA (Arizona Rehabilitation Association) joint conference, open to interested parties, on August 10-12 in Phoenix. She will send registration information to all members when it's available.

Lori asked that if anyone had not filled out and sent in their networking information to Barbara Matia, to please do so.

Next Meeting

The next meeting will be on August 16th either in Casa Grande or by telephone conference call.

The meeting was adjourned at 3:45 p.m.



*Disease Prevention Services
Office of Chronic Disease Epidemiology*

1400 West Washington Street
Phoenix, Arizona 85007
(602) 542-7333

FIFE SYMINGTON, GOVERNOR
JACK DILLENBERG, D.D.S., M.P.H., DIRECTOR

DATE RECEIVED
MAY 27 1994
REHAB. SVC. ADMIN.

May 26, 1994

Lori Pearlmutter, R.P.T., Chairwoman
Governor's Council on Arthritis and
Musculoskeletal Disorders
c/o Nancy Washburn, M.A., Community Education Specialist
Department of Economic Security; RSA
1789 W. Jefferson
Phoenix, AZ 85007

Dear Lori:

I am sending you a report of a survey that estimates the number of persons in Arizona who have arthritis. This is the first published survey that uses data obtained directly from Arizonans.

This survey estimates that 571,000 Arizonans have been told by a doctor that they have some form of arthritis. As described in the report, ADHS obtained the data by telephoning 1,847 Arizona adults in 1992 and asking them whether they have some form of arthritis, gout, bursitis, tendinitis, or lupus. We also asked whether they had been told this by a doctor. Persons who said "yes" to both questions were counted as having arthritis.

Table 1 of the report stratifies the estimated 571,000 cases by various factors (age group, race, sex, obesity status, and educational level). The Arizona data is very similar to data obtained in Ohio and Missouri.

Of particular importance is the activity limitation of persons with arthritis. The Table shows that 13.3% of Arizona's cases are limited everyday or almost everyday by their arthritis. This is a significant number of persons who are affected, often resulting in lost productivity, not to mention pain and disability.

I hope this information is helpful to the Council as you deliberate ways to help this needy group in Arizona. Please let me know if you find this information useful or if you would like additional analysis of the data.

Sincerely,

Timothy J. Flood, M.D., Medical Director
Office of Chronic Disease Epidemiology

Enclosure [CDC: MMWR V43;(17);305-9; 6May1994]

M M W R

305 National Arthritis Month — May 1994
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MORBIDITY AND MORTALITY WEEKLY REPORT

National Arthritis Month — May 1994

May is National Arthritis Month. During this month, nationwide educational activities are planned to increase awareness of arthritis. Additional information about arthritis and addresses of local chapters are available from the Arthritis Foundation, P.O. Box 19000, Atlanta, GA 30326; telephone (800) 283-7800.

Current Trends

**Prevalence of Arthritis —
Arizona, Missouri, and Ohio, 1991–1992**

Although regional and national data about arthritis can be used to develop synthetically derived measures of prevalence for states (1), few state surveys exist for determining the prevalence and impact of arthritis at that level. To measure state-specific prevalences, during 1991–1992 Arizona, Missouri, and Ohio added questions about arthritis to their Behavioral Risk Factor Surveillance System (BRFSS) surveys. This report presents BRFSS-derived estimates of self-reported prevalence of clinically diagnosed arthritis in these states and characteristics of adults who reported this disorder.

The BRFSS is a state-based, random-digit-dialed telephone survey that collects self-reported data from a representative sample of civilian, noninstitutionalized persons aged ≥18 years (2). BRFSS data were analyzed from 4688 persons who resided in Arizona (n=1847), Missouri (n=1509), and Ohio (n=1332). In Arizona, respondents were asked if they currently had some form of arthritis, gout, bursitis, tendonitis, or lupus and if they had been told this by a doctor. In Ohio, respondents were asked if they ever had been told by a doctor that they had any of those conditions. In Missouri, respondents were asked if they ever had been told by a health professional that they had arthritis. For the purpose of this report, persons who answered "yes" to any of these questions were considered to have arthritis. Respondents in Arizona and Ohio

Arthritis — Continued

also were asked how often arthritis prevented them from performing work or participating in social activities.

Prevalence rates of arthritis were 20.5% in Arizona, 23.7% in Missouri, and 24.5% in Ohio (Table 1). Prevalence increased with age, and half of respondents aged ≥ 75 years were affected. For example, in Missouri, 9.7% of persons aged 18-44 years reported having arthritis, compared with 58.4% of persons aged ≥ 75 years. Age-adjusted prevalence rates were higher for whites, women, and overweight adults (men: body mass index [BMI] ≥ 27.8 ; women: BMI ≥ 27.3). Of persons who reported having arthritis, 47% in Arizona and 46% in Ohio reported limited activity. Activity limitations occurred every day or almost every day for 13% in Arizona and 14% in Ohio.

Reported by: T.J. Flood, MD, J. Contreras, PhD, Div of Disease Prevention, Arizona Dept of Health Svcs. J. Jackson-Thompson, PhD, J. Rannit, MS, R.C. Brownson, PhD, Div of Chronic Disease Prevention and Health Promotion, Missouri Dept of Health. E. Capwell, PhD, Bur of Chronic Diseases, Ohio Dept of Health. Behavioral Risk Factor Surveillance Br, Office of Surveillance and Analysis; Statistics Br and Aging Studies Br, Div of Chronic Disease Control and Community Intervention, National Center for Chronic Disease Prevention and Health Promotion, CDC.

Editorial Note: Although there are few comparable state surveys to verify the validity of these results, at least two observations can be made by comparing these findings with national results. First, the patterns of arthritis prevalence presented in this report within age and sex groups are consistent with those in national studies (3). Second, when prevalence estimates for self-reported arthritis from the 1989-1991 National Health Interview Survey (NHIS) for persons aged ≥ 18 years are applied to the three state populations (after adjustment for region, age, sex, race, and Hispanic origin), the prevalences are lower than those in this report (Arizona, 19.8% versus 20.5%; Missouri, 19.9% versus 23.7%; and Ohio, 19.5% versus 24.5%). Possible reasons for these differences are that the surveys' or the respondents' definitions of arthritis differ across states or across surveys or because the BRFSS is more likely than the face-to-face interviews of the NHIS to result in overreporting. In addition, Ohio's and Missouri's BRFSS questions on arthritis asked about lifetime occurrence of arthritis, whereas the NHIS asked about the preceding 12 months.

Possible reasons for state-specific differences include sampling error; differences in demographic composition; or variation in the unmeasured demographic, occupational, or other characteristics of respondents. For example, some respondents may have moved to a state because they believed the climate and/or available services might improve their health. The variation may also reflect differences in the way the questions were asked; a standardized questionnaire would resolve this problem.

Data collected at the state level will help focus appropriate interventions and prevention measures (4). Such interventions should include state arthritis programs that make diagnostic, treatment, education, and rehabilitation services accessible to persons with arthritis (5) and that promote primary-prevention measures based on knowledge of risk factors, such as avoiding joint trauma, preventing obesity, and modifying occupationally related joint stress through ergonomic approaches (6). These services can reduce musculoskeletal damage, pain, and disability and substantially improve health (7).

States have used the BRFSS to measure the prevalence and impact of self-reported risk behaviors (e.g., smoking) and chronic diseases (e.g., diabetes and hypertension). The BRFSS questions about arthritis may have the same utility and can provide

Arthritis — Continued

arthritis data about special populations (e.g., Hispanics and other minority groups) that may have different disease frequency than the general population. State health departments can use such data to develop a health plan for arthritis and to set arthritis-related health objectives (4,8,9).

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Epidemiologic Notes and Reports**Tetanus — Kansas, 1993**

In 1993, two tetanus cases* were reported to the Kansas Department of Health and Environment—the first cases reported in the state since 1987. This report summarizes the findings of the case investigations.

Patient 1

On May 16, an 82-year-old man with a history of chronic obstructive pulmonary disease and recurrent pneumonia was taken to a hospital emergency department because of shortness of breath and inability to get out of bed. On May 15, he had had difficulty chewing and swallowing. Examination noted trismus ("lockjaw") and an abrasion on the right elbow, which resulted from a fall on May 14. The patient was admitted to the hospital with a diagnosis of tetanus. He had not been previously vaccinated with tetanus toxoid. Treatment included tetanus toxoid (0.5 cc) and tetanus immune globulin (TIG) (10,000 units).

While hospitalized, the patient experienced generalized tetanic spasms, followed by respiratory failure and pneumonia. He was placed on mechanical ventilation and

*Both met the Council of State and Territorial Epidemiologists/CDC clinical case definition for public health surveillance of tetanus: "acute onset of hypertonia and/or painful muscular contractions (usually of the muscles of the jaw and neck) and generalized muscle spasms without other apparent medical cause (as reported by a health professional)" (1).

TABLE 1. Weighted number and percentage of persons aged ≥18 years who reported arthritis, by selected characteristics — Ohio, 1991, and Arizona and Missouri, 1992

Characteristic	Arizona				Ohio				Missouri			
	Weighted no.*	% (95% CI) [†]	Age-adjusted prevalence [‡] (95% CI)		Weighted no.*	% (95% CI)	Age-adjusted prevalence [‡] (95% CI)		Weighted no.*	% (95% CI)	Age-adjusted prevalence [‡] (95% CI)	
Age group (yrs)												
18-44	176	10.5 (± 2.4%)	—	—	567	12.5 (± 2.7%)	—	—	204	9.7 (±2.2%)	—	—
45-64	192	30.3 (± 6.7%)	—	—	667	31.9 (± 5.7%)	—	—	329	32.8 (±4.9%)	—	—
65-74	103	38.3 (± 9.0%)	—	—	530	53.8 (± 8.4%)	—	—	213	50.4 (±7.4%)	—	—
≥75	99	52.0 (±10.2%)	—	—	194	49.2 (±10.6%)	—	—	153	58.4 (±9.4%)	—	—
Race												
White	541	21.3 (± 2.7%)	21.3	(±2.6%)	1809	25.4 (± 2.7%)	24.3	(±2.6%)	825	24.4 (±2.4%)	22.4	(±2.1%)
Other [§]	26	11.1 (± 7.1%)	12.7	(±6.9%)	158	17.8 (± 6.3%)	19.4	(±5.6%)	77	18.6 (±6.9%)	21.4	(±6.4%)
Sex												
Male	232	17.5 (± 3.5%)	18.6	(±3.3%)	729	19.3 (± 3.5%)	19.0	(±3.3%)	303	16.9 (±2.9%)	17.0	(±2.8%)
Female	339	23.2 (± 3.7%)	22.3	(±3.4%)	1237	29.3 (± 3.7%)	27.6	(±3.4%)	599	29.8 (±3.3%)	26.8	(±2.9%)
Body mass index												
Men												
≥27.8	47	19.2 (± 7.3%)	18.9	(±2.9%)	208	22.2 (± 7.4%)	23.7	(±5.6%)	126	23.5 (±6.1%)	23.8	(±5.1%)
<27.8	180	17.1 (± 3.9%)	18.0	(±5.7%)	495	18.0 (± 3.9%)	18.0	(±3.7%)	177	14.4 (±3.3%)	15.1	(±3.3%)
Women												
≥27.3	98	32.6 (± 9.2%)	32.7	(±6.9%)	417	41.5 (± 8.4%)	37.2	(±9.2%)	234	46.5 (±6.9%)	38.4	(±6.0%)
<27.3	218	20.1 (± 3.9%)	19.0	(±3.5%)	738	25.0 (± 4.1%)	25.8	(±3.9%)	341	24.3 (±3.7%)	22.3	(±3.2%)
Education												
≤8th Grade/ Some high school	114	21.4 (± 5.1%)	20.8	(±4.7%)	415	37.6 (± 7.1%)	25.2	(±5.8%)	263	42.2 (±6.5%)	28.9	(±5.6%)
High school graduate/ GED**	142	19.6 (± 4.9%)	18.9	(±4.2%)	896	24.1 (± 3.7%)	22.4	(±3.4%)	311	22.0 (±3.5%)	21.1	(±3.0%)
Some technical school/ Some college	178	18.7 (± 4.1%)	20.6	(±4.2%)	364	20.6 (± 5.1%)	25.8	(±5.6%)	194	19.5 (±4.1%)	22.5	(±4.2%)
College graduate/ Post-graduate/ Professional	137	24.0 (± 6.5%)	22.6	(±4.8%)	288	20.4 (± 5.7%)	23.1	(±6.2%)	133	17.3 (±4.5%)	22.1	(±5.5%)
Activity limitation												
Every day/ Almost every day	76	13.3 (± 4.3%)	10.6	(±4.0%)	276	14.0 (± 3.5%)	9.0	(±2.5%)	—	—	—	—
Once a week/ Occasionally	190	33.3 (± 5.9%)	38.0	(±8.3%)	619	31.5 (± 5.5%)	34.4	(±7.8%)	—	—	—	—
Never	298	52.1 (± 6.7%)	50.4	(±8.9%)	1011	51.4 (± 5.7%)	52.9	(±7.9%)	—	—	—	—
Total	571	20.5 (± 2.5%)	20.8	(±2.4%)	1967	24.5 (± 2.5%)	23.7	(±2.4%)	902	23.7 (±2.4%)	22.3	(±1.9%)

*In thousands. For Arizona, sample size=1847; for Ohio, sample size=1332; and for Missouri, sample size=1509.
[†]Confidence interval=1.96 X standard error.
[‡]Standard population for age, adjusted to the 1980 U.S. census.
[§]Numbers for races other than white were too small for separate analysis.
**General Educational Development certificate.

Governor's Council on Arthritis and Musculoskeletal Diseases
Minutes
January 11, 1994

Members Present

Tim Flood
Eric Gail
Michelle Cornett
Lori Pearlmutter
Gail Kershner Riggs
Frances Nardella
Ken Jacuzzi

Guests

David Yocum
Bridgett Walsh

Absent

Paul Cauldron
Carol Chamberlain
Edwin Lynch
Barbara Matia
David Smith
Barry Sauers
Leanna Crosby
Cele Kennedy
Kathleen Aciaoli
Carol Bulla
Linda Brickman
Bill Page

The meeting was convened at 2:05 p.m. by Chairperson, Lori Pearlmutter.

There was a motion and second to approve the minutes from the October 13, 1993 meeting as mailed. The motion passed. There was a motion and second to approve the minutes as mailed. The motion passed.

Status of Legislation

Lori advised the council that Cele Kennedy had contacted Lou Ann Preble, Republican from District 9 who has offered to sponsor the bill which would change the number in the council's quorum to the majority of the members. We would also like to eliminate "advisory" and allow all members to be voting members. In addition, there is a change to two members from two non-profit research centers in the state.

Epidemiological Study Update

Bridgett stated that she had discussed the study with a number of people with experience in grant writing (incl. Dave Yocum and Tim Flood), and had decided that there needed to be some changes made. The concern was that if the grant was not approved, she would have difficulty resubmitting for approval at a later date. She stated that two NIH reviewers had felt the survey was not focused enough. Tim Flood had advised Bridgett prior to this meeting that he had already done a prevalence study based on random telephone surveys of 2000 homes and shared his finding with the group. Arizona has an arthritis prevalence rate of 20.5% which is closed to findings of other states doing the same survey. Ohio has a rate of 24.5%, and Missouri has a rate of 23.7%. Eric Gall felt this was a surprise as we have always considered Arizona would have a higher prevalence. David was concerned that many households without phones, specially in rural

areas were not contacted. Discussion ensued and Bridgett pointed out that the national figures cited are 10-14%, so that now we have a higher number to present to legislators. Lori stated that even if the figures are slightly lower than the two other states surveyed, we still have a one in five incidence of arthritis with many of those reporting significant disability. It was also noted that Ohio and Alabama have major funded initiatives while there is no state wide effort in Arizona to reach people with arthritis in terms of health care or disability issues. Tim wished to hold on sending all the members of the written study until he had sent it for publication.

The council then discussed what the focus of our survey should be. After some discussion, the council decided that since approximately 3% of those surveyed by Tim Flood's group cited significant disability, there is a great economic impact on the state. Bridgett stated she would look into studying the prevention of disability - specifically secondary prevention (if the disease itself cannot be prevented, then perhaps disability/impairment can be prevented through education, therapy, etc.).

Rehabilitation Services Administration - Voc. Rehab. update

Lori stated that she received a letter from David Smith to send to legislators and the Governor. The issue being a complex one, Lori stated that she rewrote the letter, after some input from Roger Hodges. She thought two letters might be more appropriate, with one recognizing the problems of reduced funding, asking the legislators for more money. The draft letter was passed to the members, with some input for changes. Lori will be rewriting the letter and then sending it to all the legislators, with follow-up to the chairs of the health committees. Eric Gall agreed to work with David Smith on a second letter which addresses the problem of the order of selection, and the problem inherent in assisting the most severely disabled first without regard to potential for rehabilitation. Eric stated that David had research regarding potential for rehabilitation. He thought it might be more effective if we go to some national groups such as the Arthritis and Health Professionals Association, and the American College of Rheumatology, and ask for their support when we approach U.S. Senators and Congressman.

Membership Update

Barbara Matia spoke with Lori prior to the meeting, and stated she would contact all the members who had not been attending and ask them to resign if they would be unable to attend regular meetings. She stated she had a few resumes of those interested in being on the council.

Next Meeting

The next meeting will be held on April 12, 1994 at the Casa Grande Regional Medical Center from 2:00pm-4:00pm.

There being no new business, the meeting was adjourned at 3:55pm.

GOVERNOR'S COUNCIL ON ARTHRITIS AND MUSCULOSKELETAL DISEASES

Minutes

October 12, 1995

Members Present

Lori Pearlmuter, Chairperson
Tim Flood
Carol Chamberlain
Oscar Gluck
Michelle Cornett
Gail Kershner Riggs
Carol Wilson

Members Absent

Beverly Carol Bulla
Paul Caldron
Cele Kennedy
Dodie Londen
Eddie Lynch
Barbara Matia
Dr. Francis Nardella
Willard Page
Dr. David Wayne Smith
Dr. David Yocum

Staff

Linda C. Olson, Acting Liaison
Ellen Vercellino, Secretary

The meeting was convened at 4:10pm at the Arthritis Foundation, 777 E. Missouri #119, Phoenix, AZ by Lori Pearlmuter, Chairperson. Michelle Cornett, Gail Kershner Riggs and Carol Wilson from Tucson were hooked up via conference call.

Approval of Minutes

The following corrections were noted in the 7/26/95 minutes, Carol Wilson noted that under Old Business it was stated that she announced the Arthritis Foundation presented a Public Education Forum on arthritis. It should have stated that Carol Chamberlain announced the forum. Also, on page 2, it should read the Council accepted the offer of the Southern Arizona Chapter to present the two forums planned for Nogales & Sierra Vista. A motion was made by Gail Kershner Riggs to accept the minutes with the corrections and they were seconded by Carol Wilson. The motion was carried.

Old Business:

The Missouri Arthritis Program: A discussion was held regarding the Missouri Arthritis Program which included a Statewide Arthritis Survey. Michelle Cornett inquired as to how the Missouri Survey compared with what was reported to the Council by Dr. Flood on the study on the prevalence of persons with arthritis in Arizona done in 1993. This was a telephone survey of the population which included (1) the estimated number of persons with arthritis, and (2) the number of persons that are disabled from arthritis.

It did not address services. The percentage of the general population with arthritis in Arizona was in close comparison to other states. Arizona did not show a higher percentage of persons with arthritis. The survey showed that 100,000 persons suffered with arthritis in the State.

Ms. Pearlmutter mentioned the need for the Council to set objectives. The State of Missouri has defined what is needed for their state. Arizona has made a similiar conclusion, even though the same exact survey has not been done. Part of the survey has been done estimating the number of persons with arthritis in Arizona. Missouri developed good goals for setting up Arthritis Centers. An Arthritis Board and a State Arthritis Program Coordinator were established through a paid position by the State. There are Regional Arthritis Centers in each area.

Gail stated, that in her opinion, Missouri has probably done some of the best work than any of the states. This could be a model for the Council, if not goals and objectives. The Council could advocate more on behalf of underserved areas. Also, the Council advocates for the best Continuing Medical Education for this population. The Council needs to support this effort. The need to identify potential Arthritis Centers within the state of Arizona was noted. The goals would be to identify Regional Arthritis Centers and in conjunction with those entities develop more continuing medical education, not only in Phoenix and Tucson but in the outlying areas.

Dr. Flood mentioned that the legislature defunded the Area Health Education Centers. The centers are still in business but funding has been withdrawn.

Carol Chamberlain noted that the Missouri Plan has no legislative advocacy and that it is certainly the responsibility of the Council to add that as an additional goal.

Lori Pearlmutter stated that it would be beneficial to set one goal to achieve; set a time to achieve that goal; and then work on the next goal. The Council needs to establish timeframes and accomplish goals related to their workplan.

Gail reported that there are prepackaged programs that could be used as a boilerplate.

Carol Chamberlain suggested that the rhuematologists from Phoenix could go to the outlying areas and ask the hospitals to coordinate a program that they could get other health professionals involved in.

Dr. Flood stated that there is no central staff person from the Council and it doesn't look like there is any central agency that could coordinate a large Statewide conference. Dr. Flood suggested to do a hospital-based one hour CME type of program for their staff physicians. As a Council, a goal should be set for what is realistic for the

next 12 months. Hospitals throughout Arizona should be encouraged to put on a one hour CME regarding arthritis and its complications and the prevention there of.

The following persons have identified geographical areas that they will contact to coordinate Continuing Education programs. Carol Chamberlain volunteered the Central Arizona Chapter to focus on Payson and Prescott; Lori Pearlmutter will contact Flagstaff and Cottonwood; Carol Wilson, Michelle Cornett and Gail Kershner Riggs will coordinate Sierra Vista, Casa Grande and Yuma areas.

Gail will send material explaining the program to Lori after Carol Wilson has typed the Continuing Education Agenda on Rheumatology. Ms. Wilson will have the agenda to Lori by early next week so it can be presented to the CME person at Marcus C. Lawrence Hospital. By the end of November a date and topics should be selected. Ms. Chamberlain will also be able to contact Payson and Prescott in that time frame.

Dr. Flood volunteered to estimate the number of persons with arthritis by county to present to the CME directors. The information will be forwarded to Linda C. Olson for distribution to Council members.

Ms. Chamberlain suggested that the National Arthritis Foundation submit a plan for CME and take it as a traveling show; and that an information and referral service for people with arthritis in the state be established.

By doing the CME programs in the outlying areas, the possibility of recruiting new persons for the Council was mentioned. Anyone interested in participating would be a potential Council member.

Ms. Pearlmutter noted that she felt a more productive approach would be to select a project, set timelines, and meet as a Council as many times as necessary to get that project completed.

Ms. Pearlmutter also stated that she probably will be resigning as Chair but that she still would like to be involved in the Council.

New Business

Access to Care Issues: Dr. Smith was not available to present, but he would like to present at the next meeting.

Next Meeting Date: The next meeting will be a short teleconference on January 10 at 4:00pm.

Call to the Public

There was no public comment.

Adjournment

A motion to adjourn was made by Dr. Flood and seconded by Carol Chamberlain, and the meeting adjourned at 5:16pm.

**GOVERNOR'S COUNCIL ON ARTHRITIS
& MUSCULOSKELETAL DISEASES
MINUTES
JULY 26, 1995**

Members Present

Lori Pearlmutter, Chair
Barbara Matia
Cele Kennedy
Francis Nardella
David Wayne Smith
Carol Wilson
Carol Chamberlain
Oscar Gluck
Paul Caldron (Phone Hookup)

Members Absent

Beverly Bulla
Michelle Cornett
Timothy Flood
Dodie Londen
Eddie Lynch
Willard Page
Gail Kershner Riggs
David Yocum

Guests

Becky Rebenstorf

Staff

David Beard, Council liaison
Ellen Vercellino, Secretary

The meeting was convened at 12:40pm at the Phoenix Arthritis Foundation by Lori Pearlmutter, Chairperson.

Introductions

Members and guest introduced themselves.

Dave Beard announced his re-assignment within ARSA and that he will no longer be Council Liaison. He stated that he would be leaving following the August meeting. Mr. Beard expressed his regret at leaving the Council but was looking forward to his return to working with blind people.

Approval of Minutes

A motion was made by David Wayne Smith and seconded by Cele Kennedy to approve the minutes as mailed. The motion carried by unanimous voice vote.

Old Business

Carol Wilson announced that the Arthritis Foundation presented a public education forum on arthritis in Spanish on July 20, 1995, at the Guadalupe Senior Center.

Forty-two people attended. She expressed concern that the Governor's Council focusing on public education is a duplication of effort and resources. She suggested that the Council co-sponsor forums with the Arthritis Foundations.

The Council accepted the offer of the Tucson Chapter of the Arthritis Foundation to present the two forums planned for Nogales and Sierra Vista. The Council would assist in any way possible.

Lori Pearlmutter felt the Council needs to be more active. There was considerable discussion on the needs of citizens of Arizona citizens with arthritis. Dr. Smith suggested that many individuals with arthritis are not getting appropriate medical care as well as having many other unmet needs. He suggested that the Council be more of an advocate for people with arthritis.

The Council debated what some of those unmet needs might be. After lengthy discussion it was decided that the Council may want to survey people who have arthritis or an interest in arthritis and musculoskeletal diseases..

Dr. Smith related that the states of Missouri, Ohio, and Wisconsin have completed needs assessment. Carol Chamberlain will contact these states for a copy of their surveys and results. Ms. Pearlmutter will contact the Indian Health Service to see if they have surveyed their target population or have other demographic information that would be of use. When information is received, it will be distributed to Council members for review and comments. Mr. Beard will supply the Statewide Needs Assessment for blindness for the Council to review and compare. A teleconference was scheduled for August 30, 1995 at 4:00pm at the Phoenix Arthritis Foundation for anyone interested to discuss the surveys and to discuss the next step to be taken.

New Business

Dr. Smith announced the formation of a new multi-disciplinary team to assist the rehabilitation counselor assess their more difficult cases. He stated that about 30% of those seen, so far, are people with musculoskeletal disease and arthritis. He offered to bring several members of the team, along with a video tape demonstrating their services to a meeting. This would provide insight into the kinds of people that the vocational rehabilitation agency sees today with the diagnoses of arthritis. The video tape will show the complete process; the diagnosis, the recommendations, what the client and rehabilitation counselor propose, what action was taken at the diagnostic level, etc. The presentation will occur at the next meeting of the Council to be held on October 12 at 4:00pm at the Arthritis Foundation in Phoenix.

Barbara Matia informed members of the roof breaking ceremony at University of Arizona,, Arthritis Section, on Saturday, October 14 at 10:30am. Formal invitations are forthcoming.

Call for Public Comment:

There was no comment from the public.

Adjournment:

Cele Kennedy made a motion to adjourn and the motion was seconded by Barbara Matia. The motion passed by unanimous voice vote and the meeting adjourned at 2:06pm.

GOVERNOR'S COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES
Teleconference Meeting Minutes
March 22, 1995

Members Present

Paul Caldron
Gail Riggs
Francis Nardella
David Wayne Smith
Lori Pearlmutter, Chair
Michelle Cornett
David Yocum
Barbara Matia

Members Absent

Kathleen Acciaioli
Linda Brickman
Beverly Carol Bulla
Willard Page
Leanna Crosby
Timothy Flood
Cele Kennedy
Eddie Lynch

Guests

Denise Hampton

Staff

David Beard, ARSA liaison
Melodee Miller, ARSA secretary

The meeting, by teleconference, convened at 3:00 p.m. by Lori Pearlmutter, Chairperson.

Introductions

Members and guests introduced themselves.

Approval of Minutes

Dave Beard requested that changes in the minutes, if any, be sent to his attention otherwise the minutes were approved as mailed.

Old Business

Suggested ideas for follow-up of the February meeting were: 1.) Registry for people with auto-immune diseases in Arizona; 2.) an information hot-line number; and 3) the Council presenting public education forums in local communities.

Each of these options were discussed. Dr. Yocum stated that the Governor's Council should act, as Ms. Pearlmutter previously indicated, as a pro-active group. The Council could develop a more positive image and community identification by taking this role, especially through the hot-line and presenting public forums. It was felt that the Council should work in cooperation with the Arthritis Foundation in Phoenix and the Arthritis Foundation in Tucson if forums were presented. The resources for a hot-line are limited unless both the Tucson and Phoenix Arthritis Foundations are willing to do this task. It appears that the Arthritis Foundation Chapter of Tucson does have what is called "AIRS" - Arthritis Information Referral Services.

It was also suggested that the two Arthritis Foundation Chapters gather data and get it back to the Council so that the Council has a more clear picture regarding whats happening in Arizona. It was indicated that one of their major functions of the Tucson Chapter is education. It was suggested that perhaps the forum approach is probably the most practical avenue of the options. The hot-line would give the Council some names and concerns, but, the forums would get the Council a larger audience. It was also suggested the Council pilot two or three forums, one in South Tucson and one in Nogales. Dr. Yocum responded by suggesting that Sierra Vista might be a valid neutral site for a forum. In regard to the forums, Dr. Yocum felt that the Governor's Council should be sponsors of forums also involving Southern Arizona Arthritis Foundation with speakers from Arizona Arthritis Centers. Topics for the forums would be arthritis, lupus and auto-immune diseases. After discussion the Council recommended holding three forums in the following areas; Sierra Vista, Nogales and Guadalupe. Guadalupe was suggested due to high percentage of Hispanics and to note if there are more lupus problems in the population. This information might be helpful in the overall concern of looking at the problem of lupus in Hispanic people. Dr. Yocum asked Dr. Nardella if he would consider doing the Guadalupe forum and he agreed to assist. Dr. Yocum and an associate will be speaking at Sierra Vista and Nogales. Suggested time frames for the forums was sometime within the next two or three months.

Dr. Yocum asked if the Council wanted to make a report to the Governor on what the Council is doing. Ms. Pearlmutter responded by informing the Council that this action was on hold until the Council had actually started activities.

In the discussion of the hot-line and possible registry it was noted that the Council did not possess the resources to undertake these projects. A letter from Dr. Flood to the Centers for Disease Control and Prevention in Atlanta, was reviewed that related the Arizona Dept. of Health resources are not sufficient to fund this type of projects.

Dr. Smith suggested the Council put together some articles on arthritis and/or lupus that could be distributed to various organizations or placed into newspapers. Dr. Smith informed the Council that he had an article in the early stages, being prepared by staff at the Medical Center. He requested another member of the Council assist in editing so it would be readable by the general public. Then he suggested trying the article experimentally in the Arizona Department of Administration's publication that is sent to all State employees and retirees (60,000 people).

Gail Riggs addressed the issue of the registry. She suggested this idea is something that might be presented to the Arthritis Foundation Boards and is something they may want to get involved in through their various committees.

Other Business

Dr. Smith mentioned that he was a member of the Governor's Oversight Committee for health insurance for State employees. It had been brought to the attention of the committee by the Governor's Arizona Office of Americans with Disabilities Act (ADA) staff that disabled people with arthritis and other conditions are having difficulties in finding physicians with accessible offices. Mr. Guerry Dalrymple of the Governor's ADA Office has lead on this project. Dr. Smith asked for volunteers to work on this problem. Ms. Pearlmutter agreed to volunteer to assist. It was suggested that other councils may also wish to get involved regarding this issue. Dr. Paul Caldron addressed the issue stating that statutes are in place to ensure accessibility. He stated that anyone who does business with the public, including physicians offices, now have to comply with accessibility statutes. Mr. Beard stated that he would talk to Mr. Dalrymple and asked that volunteers for this subcommittee let him know of their interest. Dr. Smith and Ms. Pearlmutter volunteered to serve on this committee.

Announcements

The next Council meeting is scheduled for May 10, 1995, 2:00 p.m. in Casa Grande but it was suggested that the meeting be rescheduled for May 17, 1995. It was agreed upon by the group that the next meeting should follow one of the forums so that the Council could evaluate this plan of action.

Adjournment

Dr. Yocum made the motion to adjourn the meeting and was seconded by Dr. Smith. The motion carried by voice vote.

GOVERNOR'S COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES
MINUTES
February 15, 1995

MEMBERS PRESENT

Cele Kennedy
David Wayne Smith
David Yocum
Gail Riggs
Lori Pearlmutter
Michelle Cornett
Francis Nardella

MEMBERS ABSENT

Kathleen Acciaioli
Linda Brickman
Beverly Carol Bulla
Leanna Crosby
Tim Flood (*advisory*)
Eric Gall
Eddie Lynch
Barbara Matia
Carol Chamberlain (*advisory*)

GUESTS:

Cecilia Campillo
Susan Malloy
Linda Braun
Gail Ebeltoft
Lee Crosby
Renaldo Jacques

Bonnie Seashore
Leslie Boyer
Larry Cloud
Thili Kinlatilake
Bridget Walsh

STAFF:

David Beard
Melodee Miller

The meeting was convened by Lori Pearlmutter, Chairperson.

Introductions

Members and guests introduced themselves.

Approval of Minutes

A motion was made and seconded to approve the November 9, 1994 minutes. The motion carried by unanimous show of hands.

Old Business

David Beard addressed "Unfunded Mandates" as they affect the Vocational Rehabilitation Program. Mr. Beard stated that both houses of Congress are considering legislation on unfunded mandates. The President says he is willing to sign the right unfunded mandate bill. It would not be retroactive. This legislation would not ban unfunded mandates outright. It would create a parliamentary presumption within

Congress against them, and require exclusive majority votes in both houses to impose them on the States. Future bills imposing mandates on the states without the federal funds to carry them out, would be subject in Congress to a "point of order". A member of Congress could raise the point of order, another could move to waive it, and then there would be a recorded roll-call vote, if they indeed want to waive this unfunded mandate. The Vocational Rehabilitation grant to Arizona (Title I), is one of the federal programs covered by provisions of the proposed legislation.

Old Business

Leslie Boyer, MD, Medical Director of the AZ Poison Center, Clinical Toxicologist & Pediatrician, made a comprehensive presentation on TriChloroethylene (TCE) and the affects and results of human exposure to various amounts of TCE. She also provided background regarding the Nogales and South Tucson toxic exposure situations.

Cecilia Campillo, Program Manager of the El Pueblo Clinic distributed information about the clinic and presented background regarding its program in South Tucson. She requested assistance in helping them find answers to their question and in understanding their various problems. She stated that their staff wishes to network with appropriate entities. Past studies regarding TCE contamination in South Tucson were also discussed. Present data collection was discussed and suggestions made. The overriding need for health care was emphasized by several of those present. A high degree of lupus in the community has been noted. It was also suggested separating the link to TCE from the "what's the problem in the community".

Larry Clark, Ph. D. reviewed The Santa Cruz County Community Health Survey he directed, prepared under contract from the Arizona Department of Health Services. He described the methodology and discussed the clustering that was found. The study focused on two areas of concern, lupus and multiple myeloma, and the study confirmed that these two conditions occurred more frequently in Nogales than expected. Elevated blood tests were much more frequent among females than males, but that was expected regarding lupus. The study is consistent with, but does not confirm environmental risk factors for lupus.

Bridget Walsh, DO described the community survey, the interviewing process as well as other details of the study. Dr. Walsh described numbering each of the 5000 households in Nogales - divided into neighborhoods - and then with a random starting point within each neighborhood, started interviewing in a clockwise manner. So it was a random sample of the community, and then a proportion of those people volunteered to give blood. She also discussed the control group in the community of Patagonia. Patagonia residents reported a higher level of symptoms and illnesses than Nogales. But when it came to looking at the blood test, Nogales had the high levels and Patagonia didn't. Drs. Walsh and Clark explained how the data was analyzed and the conclusions. In the

conclusions, leukemia wasn't in excess and myeloma was. Most of the findings were for lupus. The association is stronger for women than for men.

Following dinner there was debate regarding the next steps the Council could take with respect to these issues. The paths of discussion centered around several possibilities: 1) Asking the Arizona Department of Health Services to begin a registry for autoimmune disease, particularly lupus in Hispanics. Developing a "hot line" for providing and gathering information regarding arthritis, lupus and autoimmune diseases was also discussed and 2) The Council should do more to educate communities on relevant issues regarding toxic exposure and resultant conditions. One of the options discussed was to sponsor an education public forum in South Tucson. It was decided that the Council would address the various options at their next meeting to be held on March 22, 1995 at 3:00 p.m. This will be a conference call meeting.

Adjournment

A motion was made and seconded to adjourn. The motion carried by voice vote.

**GOVERNOR'S COUNCIL ON ARTHRITIS
AND MUSCULOSKELETAL DISEASES
Minutes of June 19, 1996
Teleconference**

Members Present

Gail Riggs, Chairperson
Dr. Oscar Gluck, Co-Chairperson
Michelle Cornett
Dr. Tim Flood
Cele Kennedy
Dodie Londen
Carol Wilson

Members Absent

Carol Chamberlain
Barbara Matia
Dr. David Wayne Smith
Dr. David Yocum

Guests

Robert Case, Director of Harrington Center
Kathy Matt, Professor at ASU
Alex Zautra, Professor at ASU

Staff

Vince Kelly, Council Staff

The meeting was convened at 3:02 P.M. via teleconference at the Arthritis Foundation, 6464 E. Grant Road, Tucson, AZ and at the Harrington Arthritis Research Center, 300 N. 18th Street, Phoenix, AZ by Gail Riggs, Interim Chair. Dodie Londen, Michelle Cornett and Dr. Tim Flood were also linked in on the conference call meeting.

APPROVAL OF MINUTES

The motion to approve the minutes as presented was made by Dr. Gluck and seconded by Cele Kennedy. The motion was carried.

OLD BUSINESS

Election of the Chair and Co-Chair: Gail Riggs stated that, although she and Dr. Gluck had been nominated and elected as co-chairs at the previous meeting, to assure that the election was fully in accordance with the Open Meeting regulations promulgated by the Attorney General, a new vote would be taken to confirm the results of the previous election. Dodie Londen re-nominated Gail Riggs as Chair and Dr. Gluck as Vice-Chair of the Council; Carol Wilson seconded the motion and the two were unanimously elected by all the members present.

Nomination of New Members: Dr. Gluck and Gail Riggs read the list of persons nominated for re-appointment or appointment to the Governor's Council of Arthritis and Musculoskeletal Diseases:

Michelle Cornett (re-appointment)
Steve Hollander, M.D.
Kelly Wyland
Lee Brest
Alex Zautra, Ph.D.
Kathy Matt, Ph.D.
Robert Case
John Svick

Gail Riggs moved for acceptance of the nominees; Carol Wilson seconded the motion. The nominations were approved by all members present. The Chair of the Council will forward the list of nominees to the Governor's Office of Boards and Commissions. Ms. Riggs announced that there were still two or three openings for new members: one from among persons with arthritis or some other form of musculoskeletal disease; one from the general community; and one from among professional health workers. The Chair then asked for further nominations or suggestions. Dodie Londen suggested that the new nominees be recruited from other regions of the state besides Phoenix and Tucson. Cele Kennedy suggested that any new candidates should be nominated and voted on in the next Council meeting. A new member to replace Carol Chamberlain, the representative of the Arthritis Foundation/Phoenix Chapter, should also be sought, since Ms. Chamberlain indicated she will no longer be able to serve on the Governor's Council.

COMMITTEES

Ms. Riggs announced that she was establishing a Resource and Planning Committee. Members are Gail Riggs, Oscar Gluck, Carol Chamberlain and Bob Case. A Chair will be appointed when the new committee meets on August 1, 1996 at 1:00 P.M. The meeting will be held at the Harrington Arthritis Research Center, but only Committee members are required to attend.

Ms. Riggs said it was essential to interface with other Councils, Foundations and Associations, such as the Council on Aging, the Del Webb Foundation, the American Osteopathic Association, and the Arizona Medical Association. Cele Kennedy pointed out that she is also a member of the Disability Prevention Council. Dr. David Wayne Smith also serves on the Governor's Council on Blindness and Visual Impairment.

GOALS AND ACTIVITIES OF THE COUNCIL

Dr. Oscar Gluck stated that he would like to have a summary of all the Arthritis Council's accomplishments and activities since its inception. Cele Kennedy and Vince Kelly agreed to provide such a summary. Dr. Gluck further stated that he would like the Council to set a specific, limited list of goals to accomplish this year. He suggested the

possibility of having the Council develop a brochure in Spanish for persons suffering from arthritis or some other musculoskeletal disease. Another possibility would be a conference on Arthritis to be held in early January 1997. The Harrington Arthritis Research Center, ASU, the U of A, the Arthritis Foundation are all represented on the Council and should be able to participate in such a conference to draw public attention to a serious medical problem that affects more than 700,000 persons in Arizona.

Cele Kennedy suggested improving communications on arthritis issues by setting up a computer network with a special web site for information on arthritis.

Ms. Riggs announced that the next full Council meeting would be held on Thursday, September 12, 1996 from 1:00 to 3:00 P.M. at the Harrington Arthritis Research Center in Phoenix. The focus of the meeting will be on goals and objectives for the coming year. Council members were urged to attend the Workshop on "Mapping the Road to Effective Committee Outcomes" at the 1996 RSA Training Conference. The Workshop will be presented between 1:00 and 4:00 P.M. at the Marriott Mountain Shadows at 5641 E. Lincoln Drive, Scottsdale, AZ.

Another suggestion was that Council members and the Council staff research current legislation that can affect persons with musculoskeletal diseases, such as legislation to fund the Arizona Dept. of Health and its research and treatment projects.

CALL TO THE PUBLIC

Because of the limitations of the teleconference situation, a call to the public was not formally made. However, at each of the major meeting sites a general discussion was continued.

A suggestion made by Dr. Zautra was that the Governor's Council on Arthritis and Musculoskeletal Diseases could sponsor a Speakers' Bureau to increase public awareness. It would be especially important to inform young people in school about ways of preventing or ameliorating the effects of some forms of arthritis and rheumatism.

ADJOURNMENT

Dr. Gluck moved that the meeting be adjourned; Cele Kennedy seconded. Without objection the meeting was adjourned at 3:05 P.M.

**GOVERNOR'S ADVISORY COUNCIL ON ARTHRITIS
AND MUSCULOSKELETAL DISEASES
MINUTES
MARCH 21, 1996**

Members Present

Lori Pearlmutter, Chairperson
Dr. Oscar Gluck*
Cele Kennedy
Barbara Matia
Gail Kershner Riggs*
Dr. David Wayne Smith*
Carol Wilson*

*Teleconferenced

Members Absent

Beverly Carol Bulla
Carol Chamberlain
Michelle Cornett
Dr. Timothy Flood
Dodie Londen
Eddie Lynch
Dr. Francis Nardella
Dr. David Yocum

Guests

Robert Case, Director, Harrington Arthritis
Research Center
Dr. Gail Cassel, Chair of Microbiology,
University of Alabama
Patricia Riach, Member of the Public with Arthritis
Lucy Smith, Member of the Public with Arthritis
Dr. Virgil Steinberg, Member of the Public

Staff

Vince Kelly, Council Staff
Ellen Vercellino, Secretary

Meeting was called to order by Lori Pearlmutter, Chairperson, at 4:15 PM at the Harrington Arthritis Research Center in Phoenix, AZ.

WELCOME AND INTRODUCTIONS

Members and guests introduced themselves.

APPROVAL OF MINUTES

Dr. David Wayne Smith made a motion to approve the minutes as written. The motion was seconded and the minutes were approved.

OLD BUSINESS

Discussion of the Biennial Report: Mr. Pearlmutt reported that she has received information from Vince Kelly, Carol Wilson, Tim Flood, and the Arthritis Foundation to be included in the Annual Report. She has also received information from Dr. Cassel regarding the anticipated number of people who will contract arthritis in the future. As soon as all the information is received, she will summarize it and send it to all Council members for their review and input.

Report of the Nominating Committee: Barbara Matia and Cele Kennedy reported that legislation calls for the Council to sunset in July 1997. The Nominating Committee discussed the possibility of dissolving the Governor's Council on Arthritis and Musculoskeletal Diseases and having the Southern Arizona Chapter and the Central Arizona Chapter of the Arthritis Foundation assume the responsibilities. Ms. Matia felt that this should be discussed by the Council. Gail Riggs' opinion is that the Council should not be dissolved; that the Council is another way to get visibility for arthritis and arthritis chapters in the state. Ms. Kennedy stated that there is time to explore the feasibility of requesting new legislation for the Council to continue, or to comply with the statute and sunset in July 1997. Ms. Kennedy's opinion is that the Council and the arthritis chapters are duplicating their efforts. Ms. Kennedy sits on the Governor's Council on Disability and Prevention. This Council is willing and eager to accept members from the Governor's Arthritis and Musculoskeletal Council as part of their Council because, globally, the two Councils are addressing the same issues. Dr. Smith expressed the concern that not a lot is being done for people who are on the lower level of the socio-economic scale and who are knocked out of the work force because of arthritis. If the Governor's Council on Disability and Prevention is going to pick up on that responsibility, Dr. Smith would just as soon see the Governor's Council on Arthritis and Musculoskeletal Diseases sunset in 1997 and let the other Council assume the responsibility. Dr. Gluck is also against dissolving the Council and volunteered to help keep the Council going.

NEW BUSINESS

Election of New Chair: Gail Riggs volunteered to be Chair with Dr. Oscar Gluck as co-chair with stipulations. They would like more information before officially accepting the position.

Cele Kennedy made a motion that Gail Riggs and Dr. Gluck co-chair the Council with stipulations. Lori Pearlmutt seconded the motion. A voice vote was taken of all members participating in the teleconference. Absent members were later contacted to see if they were in agreement with the choice of Gail Riggs and Dr. Oscar Gluck as chair and co-chair respectively "with stipulations". (Since some members were not able to be contacted, and appear to have moved or left the state, there was some doubt as

to whether a quorum was present and whether the vote was valid. Accordingly, a new vote will be taken at the next teleconference meeting on June 19, 1996.) The election of Council officers will be held at the next Council meeting in order to conform with the Open Meeting Law. The members will also be informed that the Council is scheduled to sunset July 1997.

CALL TO THE PUBLIC

A call to the public was made with comments as follows:

Dr. Cassel, the guest speaker at the Council's public lecture on "The Role of Infection in Arthritis", stated that she would feel uncomfortable expressing an opinion on dissolving the Council without reviewing the activities of the Council. She did state that, in terms of partnering with other organizations, one consideration would be the possibility of the Council enlarging its efforts and enlarging its constituency by cooperation and collaboration among organizations with similar interests.

Dr. Steinberg expressed his opinion regarding the Council. He encouraged the Council to continue the remaining year. He reported that there are exciting developments coming in arthritis and the Council will be needed to evaluate them.

Robert Case, Executive Director of the Harrington Arthritis Research Center, would like to see the Council continue. He will give his time and effort to this cause.

Lucy Smith commented on the treatment that people with arthritis are receiving who have no money or insurance. She was on unemployment making \$88 a week when she tried to get help from AHCCCS. She was told that she made too much money.

ADJOURNMENT

A motion to adjourn was made by Cele Kennedy and seconded by Barbara Matia. The meeting was adjourned at 5:10 PM.

**GOVERNOR'S COUNCIL ON ARTHRITIS
AND MUSCULOSKELETAL DISEASES**

**Minutes
January 10, 1996**

Members Present

Lori Pearlmutter, Chairperson *LP*
Beverly Carol Bulla
Carol Chamberlain
Dr. Timothy Flood
Dodie M. Londen
Barbara Matia
Dr. David Wayne Smith
Carol Wilson

Members Absent

Michelle Cornett
Dr. Oscar Gluck
Cele Kennedy
Eddie Lynch
Dr. Francis Nardella
Willard Page
Gail Kershner Riggs
Dr. David Yocum

Staff

Vince Kelly, Council Liaison
Ellen Vercellino, Secretary
Linda C. Olson, Manager,
Planning & Evaluation

The following members were teleconferenced: Lori Pearlmutter, Chairperson, from Flagstaff, AZ; Dr. Timothy Flood from El Paso, Texas; David Wayne Smith and Carol Wilson from Tucson.

APPROVAL OF MINUTES

David Wayne Smith made a motion to approve the minutes as mailed and Carol Chamberlain seconded the motion. The motion was approved.

OLD BUSINESS

Lori Pearlmutter reminded the Council that she sent her resignation from the Council due to new responsibilities in Flagstaff. She wishes to continue to serve as Chair of the Council until the Biennial Report for 1994-1995 is completed, probably in March 1996. After her resignation becomes effective, she will be available to help the Council on projects from Flagstaff, if needed.

Discussion on Progress Regarding Contacting the Allied Health Professionals and Physicians to Offer Continuing Education Programs in the Area of Arthritis: Carol

Chamberlain reported that she is in the process of setting up Public Education and Community Service projects in Prescott and Payson. Ms. Pearlmuter reported that Dr. Mike Marsick spoke to a group of doctors in Flagstaff regarding Continuing Medical Education for doctors, nurses, physical and occupational therapists, and students in Flagstaff. She is working on setting something up at the Marcus J. Lawrence Hospital in Cottonwood. Carol Wilson stated that in Southern Arizona the focus has been on community education. The outlying areas have not been contacted for professional education. There was a presentation given by Shannon Howe in Yuma. Nogales is in the process of developing community education projects dealing with arthritis and musculoskeletal diseases.

NEW BUSINESS

Ms. Pearlmuter introduced the new Council Liaison, Vince Kelly. She then suggested doing an Annual Report to the Governor before she leaves the Council. Linda Olson suggested that one be done on activities completed in the last couple of years. David Wayne Smith suggested that the Missouri Plan be summarized and included in the report as it could be used in the future. Linda Olson suggested that data from Dr. Flood's Statewide Survey on the estimates of persons with arthritis and musculoskeletal diseases in each county of Arizona be included. Dr. Flood volunteered to provide a one-page summary of the report. It was suggested that a two-year report could be accomplished. Dr. Smith inquired about the presentation on Lupus done in Nogales.

The following assignments were given for the Annual Report:

Ms. Pearlmuter will summarize the study done by Missouri.

Carol Chamberlain and Carol Wilson will summarize the public and professional outreach done by the Arthritis Foundations.

Tim Flood will summarize his study.

David Wayne Smith will inquire as to what exactly was done in the Nogales area. He suggested that it might be helpful if people understand the roles of the different agencies and put something in about the role and function of the private sector, two Arthritis Chapters and the role and function of the State Vocational Rehabilitation Agency with respect to people with arthritis and musculoskeletal diseases who have employment potential. He also suggested that Vince write this part of the report and that he include some statistics on VR clients who suffer from arthritis, rheumatism and other musculoskeletal diseases.

The summaries should be sent to Lori Pearlmuter by February 16, 1996. She will compile the information and forward it to David Wayne Smith for editing.

Dr. Flood asked about an Arthritis Foundation program called "Arthritis Self-Help Program". Carol Wilson reported that it is a six-week class that helps people understand and manage their arthritis better to improve the quality of their life. Carol Chamberlain reported that there are a lot of classes in Phoenix on a quarterly basis.

Ms. Chamberlain volunteered to do a synopsis of the services offered by the Arthritis Foundation and the numbers reached.

Barbara Matia had a telephone conversation with Dr. Gail Cassell, Chairperson of the Department of Microbiology of the University of Alabama. She leads an international movement on infection and AIDS. There has been enough research done at the University of Alabama that infection in arthritis can no longer be ignored. She has been invited to Arizona and will spend the week of March 18-22 in Arizona. It was suggested that ASU, UofA, the Arthritis Foundation, and the Harrington Center might be able to host an event for that week. It was suggested that letters be sent out to other Councils, counselors, RSA staff, rheumatologists, and public notices be posted. Ms. Matia suggested that there be two sessions in Phoenix and two sessions in Tucson. There would be a presentation for the lay people and one for the professional people in each city.

The Nominating Committee, Cele Kennedy and Barbara Matia, will try to meet and nominate two people to fill the vacancies created by the resignations of Dr. Caldron and Ms. Pearlmutter. Members were asked to be thinking about nominations for the Council and the Chair to be discussed at the next meeting.

Lori Pearlmutter's resignation from the Council will not become effective until the Annual Report is finished.

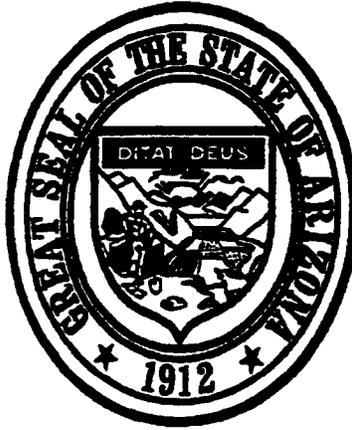
The next meeting is scheduled for March 20, 1996 in conjunction with Dr. Cassell's presentation. Vince Kelly will send out a flyer with the information.

CALL TO THE PUBLIC

There was no public comment.

ADJOURNMENT

Carol Chamberlain made a motion to adjourn. The motion was seconded and the meeting adjourned at 4:59 p.m.



**GOVERNOR'S COUNCIL ON ARTHRITIS
AND MUSCULOSKELETAL DISEASES**

BIENNIAL REPORT

SFY 1995-1996

Governor's Council on Arthritis and Musculoskeletal Diseases Biennial Report: State Fiscal Years 1995-1996

Council Purpose

The purpose of the Arizona Governor's Council on Arthritis and Musculoskeletal Diseases is to bring together organizations and individuals with a knowledge and basic interest in this important health problem and to develop recommendations the state may adopt to help meet the needs of victims of these diseases.

Council Background

This advisory council was established under Arizona Laws 1987, ch.258, item 2, which was approved by the Governor on May 8, 1987. It was originally located in the office of the Governor, but later it was moved to the Department of Economic Security, and is provided support by the Rehabilitation Services Administration of DES. The legislation mandates the following duties to the Council:

- advise appropriate state agencies, the Governor and the Legislature on matters and issues relating to arthritis and musculoskeletal diseases;
- review and make recommendations, plans and strategies for meeting the needs of persons with arthritis and musculoskeletal diseases statewide;
- in cooperation with related organizations, conduct a comprehensive program of public and professional education to heighten awareness of the capabilities, potential and needs of persons with arthritis and musculoskeletal diseases.
- serve as a repository of information on arthritis and musculoskeletal diseases, referral procedures and demographics of these diseases;
- monitor programs and services for persons with arthritis and musculoskeletal diseases to encourage efficient and coordinated use of resources in providing services.

Membership

At the beginning of 1996 the Governor's advisory council consisted of 19 members with two vacancies. The Council chairperson was Lori Perlmutter. A current membership list is included as an attachment in this report. The list includes members' names, addresses, phone numbers, the designated category of member status, and term expiration dates. Five of the members serve in an advisory/ non-voting capacity.

The chair of the membership committee, Barbara Matia, is seeking recommendations for potential new members who can enhance the Council's

ability to educate and advocate on behalf of the 570,000 or more persons with arthritis and/or musculoskeletal diseases in Arizona. A set of new nominations for membership has been presented to the Governor's Office of Boards and Commissions for the Governor's approval.

The Council membership includes a broad representation of ethnic and cultural backgrounds, as well as wide geographic distribution

Number and Location of Meetings

The Council membership currently includes persons from the north, central and southern part of the state, particularly in the cities of Flagstaff, Phoenix, and Tucson. Because of their central locations, Phoenix and Casa Grande have been the sites for all of the meetings. However, to reduce the burden of travel on members in Flagstaff and Tucson, a number of Council meetings have been teleconferenced with members attending a central location in Tucson or Phoenix, and other members being linked up at their homes or offices..

The Council has met four times in 1994 and five times in 1995., thereby complying with the mandated four quarterly meetings per year. At least six meetings are anticipated for 1996.

Council Activities

Professional and Public Education

In keeping with its mandate to "conduct a comprehensive program of public and professional education...." The Governor's Council has collaborated with the Arthritis Foundation, regional medical centers, the University of Arizona's Health Science Center, and the Harrington Arthritis Research Center is presenting a series of workshops and presentations on arthritis-related issues in the following areas :

Prescott	Flagstaff	Tucson
Phoenix	South Tucson	Nogales
Payson	Cottonwood	

Presentations have been made by distinguished professional health specialists in the field of rheumatology, such as Dr. Brigett Walsh, Dr. Leslie Boyer, and Dr. Mike Marasek of the University of Arizona and Dr. Gail Cassell of the University of Kentucky. Dr. Cassell's presentations on "The Role of Infection in Arthritis" provided new insights from her extensive research on this topic. One presentation was directed toward the continuing medical education of physicians and other health care professionals; a second presentation was given for the benefit of the general public.

Coordination with Other Councils, State Agencies, and Public and Private Organizations

In order to assure broad representation on the Council, some members are Ex-officio representatives of the DES/ Rehabilitation Services Administration, the Arizona Department of Health Services, and the University of Arizona Department of Rheumatology. In addition, members included directors of local Arthritis Foundation chapters, health professionals from Arizona State University, the Arizona Health Sciences Center, the Harrington Arthritis Research Center and Flagstaff Medical Center, and a member of the Arizona legislature. Accordingly, communication among these various institutions is facilitated by the members' participation in Council and committee meetings.

At least two of this Council's members have joint memberships on other statewide councils: the Governor's Council on Blindness and Visual Impairment, and the Disability Prevention Council. The Council's liaison to RSA also serves with the Governor's Council on Blindness and Visual Impairment, and the State Rehabilitation Advisory Council (SRAC). Information about common concerns or relevant activities is routinely shared among the Councils. For instance, reports of public comments obtained in public forums conducted by the Statewide Independent Living Council (SILC) and SRAC were provided to the Governor's Council on Arthritis and Musculoskeletal Diseases for possible action or response to citizens' concerns that related to the mission of the Arthritis Council.

Members of the Governor's Council on Arthritis and Musculoskeletal Diseases participated with members of other Councils in a joint training session provided by RSA and which was specifically designed to enhance Council members' planning, problem-solving and decision-making skills. Members of the various councils were mutually able to share their knowledge and skills about Council and committee problems, solutions, and procedures.

Advocacy

Council members continue to have a voice in the provision of services by RSA. Individual Council members have acted as advocates and mediators for persons with arthritis and/or musculoskeletal diseases so that they would receive fair consideration in the determination of eligibility or for receiving needed services. The Council advised the RSA administrator on the opening of the Order of Selection, which allowed for the provision of services to clients classified as "severe" as well as those who were "most severe."

Council members have actively monitored current and pending legislation they considered pertinent to the arthritis community. Individual members have contacted legislators to recommend approval or disapproval of specific bills or parts of bills pertaining to persons with arthritis.

This Council has advocated for increased financial support by the Arizona legislature for the Vocational Rehabilitation Services program of DES/RSA and for the Disability Prevention Center of the Department of Health Services.

This Council urged the national center of the Arthritis Foundation to change its policies that now tend to preclude the provision of direct services to clients with arthritis and related diseases. The Council has encouraged the Southern Arizona and Central Arizona chapters of the Arthritis Foundation to provide classes and public lectures to arthritis patients, their families and the general public. This Council collaborated with the Arthritis Foundation by co-sponsoring public presentations to the largely Hispanic population of Nogales and South Tucson.

This Council has been an active advocate to the Arizona Department of Health Services in support of contracts and grants to conduct Community Health Surveys, such as the Santa Cruz Community Health Survey. The Governor's Council on Arthritis and the Arthritis Foundation cooperated in supporting public presentations of the findings of the survey in Santa Cruz County, specifically in Nogales, Arizona. Some findings of the study:

- Santa Cruz County has a statistically significant excess number of incident cases of multiple myeloma;
- the area defined by Nogales and Rio Rico has a high prevalence of Lupus (Systemic Lupus Erythematosus);
- these two lymphocyte disorders are related to a malfunction of the body's auto-immune system, and may be the result of complex environmental exposure to biologic or chemical agents;
- given the high degree of concern among the residents of this area, many of whom are Hispanic and who may have greater vulnerability to these diseases, the results of the study warrant further investigation.

The Governor's Council on Arthritis advocated and supported the development of a new epidemiologic study on the prevention of arthritis and other diseases. Due to the difficulty in obtaining funding, the project has been postponed but it remains an important objective to be achieved in the near future by the Council in collaboration with state agencies, universities, and/or regional medical centers specializing in arthritis and musculoskeletal diseases.

This Council gave strong support, and will continue to seek additional support, for an important study on the prevalence and impact of functional limitations in Arizona. Since Vocational Rehabilitation Services tends to focus primarily on functional limitations which are or may become impediments to employment, rather than on the disease or medical condition which causes them, the results of such a study would be valuable in determining which services to provide in order to more effectively rehabilitate clients with arthritis and musculoskeletal diseases, as well as many other physically disabling conditions. (See the attached project description.)

A member of this Council, who is also a health specialist with the Arizona Dept. of Health, compiled estimates of the incidence of a variety of common diseases or disorders for all of the counties and for Arizona as a whole. (See attached sample of Estimates for 1996.) Just for arthritis alone, it is expected that the number of reported cases will increase by over six percent (6%). It is urgent that timely provision be made to meet the medical and rehabilitation needs of these new victims of disease. It is even more urgent that means be taken to prevent illness from occurring or from becoming more severe through the provision of improved public health education and early screening and treatment, particularly in more remote areas of the state.

Health Issues Relating to Arthritis

Unfortunately, there is still a great deal of ignorance among the public and some general practitioners as to the origin and nature of arthritis. Some forms of arthritis , such as serum sickness, are related to allergies; others are due to the use of drugs, including some prescription drugs. Some forms of rheumatic disease are associated with infectious agents, such as bacteria or viruses. Rickets results from a lack of vitamin D and insufficient exposure to sunlight.

Any of the rheumatoid diseases can range from "minor" to disabling, and can be acute or chronic. The image often presented in the media is that arthritis is a minor sort of annoying condition that can be readily relieved by taking an aspirin or two. The sordid truth is that arthritis is often a progressive disease that leads to painful and disabling deformities and, in some cases, to death. Over 570,000 persons in Arizona have been diagnosed as having arthritis or a related disease. The actual number is probably much greater as many do not seek treatment but suffer in silence. Since arthritis is closely related to infection, both as a result and as a factor in causing infections, it is important to realize that infectious disease is the third leading cause of death in the United States, and accounts for one-fourth of total health-care costs

The Governor's Council on Arthritis and Musculoskeletal Diseases has selected as one of its major goals to inform the public and the health community about the dangers and causes of arthritis and related diseases, about methods of prevention, treatment and rehabilitation that are currently available but underutilized, and the urgent need for financial support by the state and federal government, by private foundations and the public to initiate and support scientific research on this group of serious, widespread diseases.

Recommendations of the Governor's Council on Arthritis and Musculoskeletal Diseases

This advisory council has provided advice to the administrator of the Rehabilitation Services Administration through the minutes of its regular meetings. The Council has also requested that the RSA administrator be appointed as the ex-officio member of the Council to represent the Department of Economic Security and RSA. The Council is pleased that the administrator has agreed to undertake that responsibility.

This Council recommends that RSA include training on the disabling effects and functional limitations resulting from arthritis and musculoskeletal diseases in the ongoing education of RSA staff. Members of the Council are available to assist in providing this training.

- This Council recommends that a state plan for the prevention, detection, treatment and remediation of the effects of arthritis and musculoskeletal diseases be developed. Major responsibility for the development of such a plan should be vested with the Arizona Department of Health. Other states, such as Missouri, have developed and implemented such a plan with notable success. (See attached copy of "Arthritis: The Problem, the Status, the Plan.")
- Preliminary to developing a state plan, a comprehensive survey of the health needs of the residents of the state should be conducted to identify the greatest dangers to health, the attitudes of the public toward these health hazards, and the resources currently available for prevention, diagnosis, treatment and rehabilitation.
- As part of the statewide plan, a network of regional arthritis centers should be established in selected locations in order to assure the accessibility of assessment and treatment of arthritis and related diseases.
- Increased emphasis should be placed on the continuing education of health professionals concerning arthritis and musculoskeletal diseases. The Arizona legislature should provide adequate funding to the Dept. of Health Services to provide for this service.
- Increased emphasis should be placed on the education of the general public about the serious nature of this disease, on the importance of early diagnosis and treatment, and on the resources which are available for diagnosis and treatment. This educational effort should include the education of young

people in school about the behaviours that can cause or aggravate arthritis and related diseases.

- Excellent local exercise programs, designed by health care professionals, are being provided by Arthritis Foundation chapters in a number of locations in the state. However, there is a need to increase the availability of these valuable programs, particularly in outlying regions. Special attention should be given to providing exercise programs for older citizens, and especially older women, who are particularly prone to the progressively disabling effects of arthritis.
- Informational brochures on arthritis, rheumatism and other musculoskeletal diseases should be made available at public expense and in language that is readily understandable. This would include printing brochures in Spanish for those Hispanic persons with limited knowledge of English.
- Since arthritis and related diseases affect a sizeable number of Arizona residents (and that number is likely to increase due to the influx of older, retired persons coming to enjoy Arizona's healthful climate), the Arizona Legislature should increase its funding:

--of the Arizona Dept. of Health Services and AHCCCS in order to improve the quality of health care for persons at risk or suffering from arthritis and other crippling musculoskeletal diseases. Timely measures of prevention, diagnosis and treatment would result in considerable savings of money to the state and its citizens;

--of the Independent Living Centers that have been established in certain locations in Arizona with Federal funding. Increased support is needed so that these centers can improve both the quality and the extent of their services;

--of the DES/ RSA's programs of Vocational Rehabilitation Services and Independent Living Rehabilitation Services. Consistent full-match funding by the Legislature would assure a larger federal grant to support these vital yet undersupported programs.

According to "The Arthritis Fact Book for the Media" (Atlanta, GA: Arthritis Foundation, 1986):

"Arthritis is America's number 1 crippling disease. It has been estimated that \$14 billion is lost annually in wages and medical bills. Arthritis accounts for 500 million days lost from work. This disease is the leading cause of industrial absenteeism and, after heart disease, the second leading cause of disability payments."

GOALS AND OBJECTIVES FOR 1996-1997

The Resources and Planning Committee of the Governor's Council on Arthritis and Musculoskeletal Diseases has proposed the following goals and objectives to the Council as the major areas on which it will focus its energies and attention during the coming year:

1. Establish a registry of arthritis victims in Arizona, with special focus on the incidences of Juvenile Arthritis and Rheumatoid Arthritis, the most virulent forms which cause crippling, loss of mobility, loss of employment and early mortality. Contrary to a common misconception, the prognosis for Rheumatoid Arthritis and Juvenile Arthritis is worse than some forms of cancer or heart conditions. Rheumatism affects the whole body with joint destruction occurring within six months of the on-set of the disease. Those rheumatism sufferers who were employed at the onset of the illness are generally on disability or unemployed within five years.

While available statistics suggest that only 17% of Arizonans suffer from Arthritis, the actual figure is unknown and is probably much higher. Missouri, for instance, estimates that 33% of its population suffers from arthritis or other musculoskeletal disease. As actual cases of Juvenile Arthritis and Rheumatoid Arthritis are documented through blood testing, awareness of the gravity of the problem and of those areas where the problem is most severe (such as on the Pima and Tazono O'odham reservations) will be heightened and adequate measures for prevention, detection, treatment and rehabilitation can be undertaken.

2. Securing a full-match of state funding to draw down the maximum available federal funding for the Arizona Department of Economic Security and the Arizona Department of Health Services.

The DES state appropriation was reduced by \$1.1 million as of July 1, 1996. This reduction in operating funds will have a corresponding loss of, perhaps, an additional million dollars, which will affect the quantity and quality of services available to the poor, to children, the aged and disabled.

Short-term Goals

3. Interface with other State Councils, such as the Statewide Independent Living Council, the Council on Aging, and the Disability Prevention Council, as well as publicly funded programs, such as the Arizona Technology Access Program, avoid gaps and/or unwarranted duplication of effort in their areas of advocacy or concern, but especially to develop a synergistic force for the accomplishment of their mutually-shared objectives.

- 4. Establish linkages with professional health organizations in Arizona, such as the Arizona Medical Association and the Arizona Osteopathic Association, etc. for the purpose of providing state-of-the-art information and instruction concerning the nature and treatment of rheumatic diseases to health professionals.**
- 5. Develop a strong communication link among the University of Arizona Arthritis Center, the Harrington Arthritis Research Center, the Northern Arizona University's Institute of Human Development, Arizona State University, the Arthritis Foundation, etc. to explore areas of mutual concern for collaborative efforts for the benefit of persons suffering from arthritis and musculoskeletal diseases. Specific research projects, such as the effect of certain physical therapies or psychological techniques (e.g., bio-feedback) in the alleviation of pain and the amelioration of emotional stress and depression. These institutions can provide a medium for the dissemination of research findings to health professionals and the general public.**
- 6. Provide direct input into the planning and implementation of training programs for administrative and professional staff of the Rehabilitation Services Administration. Knowledge of the functional limitations and emotional concomitants of arthritis and musculoskeletal diseases should be part of the professional knowledge of Vocational Rehabilitation Counselors and Independent Living Rehabilitation Counselors.**
- 7. Provide for the continuous update and dissemination of current research reports in rheumatology and related health disciplines. This information can be disseminated through public presentations, the media, printed reports, and audio- or video-tapes of live presentations. The collaborative efforts of many individuals and organizations will be required to achieve this purpose.**
- 8. Advocate and seek financial support for the establishment of a chair of pediatric rheumatology at the University of Arizona's School of Medicine. The two specialists in that field have left the University and there are currently no medical specialists in this field to study and treat children with juvenile arthritis or to provide training on the diagnosis and treatment of this virulent disease at Arizona's only M.D.-granting Medical School.**
- 9. Develop a realistic, specific budget, as well as a plan of specific objectives and activities, for achieving each of the above longer-term and short-term goals. The Council members will research funding sources and will actively participate in procedures required for obtaining the necessary funds.**

ATTACHMENTS

- 1. Current Council Membership List**
- 2. Notice of Public Meeting on "The Role of Infection in Arthritis"**
- 3. Project description: Assess the Prevalence and Impact of Functional Limitations in the State**
- 4. Estimates for 1996 of victims of arthritis and other diseases in Arizona, by County**
- 5. " Arthritis: the Problem, the Status, the Plan" (A report by the Missouri Arthritis Program, Jan. 1988)**



STATE OF ARIZONA
EXECUTIVE OFFICE

FIFE SYMINGTON
Governor

ADVISORY COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES
A.R.S. 41-971 / 972

The Honorable Carolyn Allen
Arizona House of Representatives
1700 W. Washington
Phoenix, AZ 85007

Member w/Arthritis
542-4225 (O)
Term Expires: 1/18/99
Replaced: Willard Page

Lee Brest
1926 E. Granito Vista
Tucson, AZ 85713

Member w/Arthritis
624-1375 (H)
Term Expires: 1/18/99
Replaced: Ken Jacuzzi

Paul H. Caldron, D.O.
3330 N. Second Street
Phoenix, AZ 85012

Rheumatologist
759-0716 (H) / 234-3434 (O)
Term Expires: 1/19/98
Replaced: Reappointment

Carol Chamberlain
777 E. Missouri, #119
Phoenix, AZ 85014

**Advisory Member-Arthritis
Foundation Representative**
264-7679 (H)

Michelle Cornett
4737 N. Geronimo
Tucson, AZ 85704

Public Member
293-2843 (H) / 626-6041(O)
Term Expires: 1/18/99
Replaced: Reappointment

Dr. Timothy Flood
1400 W. Washington
Phoenix, AZ 85007

**Advisory Member - Dept of Health
Services Representative**
230-5881 (O)

Oscar Gluck, M.D.
AZ Rheumatology Center
6036 North 19 Ave, #312
Phoenix, AZ 85015

Professional/Rheumatologist
246-1964 (O)
Term Expires: 1/19/98
Replaced: Leanna Crosby

**ARTHRITIS & MUSCULOSKELETAL ADV COUNCIL
PAGE TWO**

Cele Kennedy
505 W. Solano Drive
Phoenix, AZ 85013

Member w/Arthritis
277-3713 (H)
Term Expires: 1/20/97
Replaced: Reappointment

Pami Kowal
7921 E. Willetta Street
Scottsdale, AZ 85257

Member w/Arthritis
946-6172 (H)
Term Expires: 1/18/99
Replaced: Ed Lynch

Dodie M. Londen
33 Biltmore Estates
Phoenix, AZ 85016

Member w/Arthritis
956-7971 (H) / 957-7770 (O)
Term Expires: 1/19/98
Replaced: Vacant Position

Barbara Matia
4829 East Beryl Avenue
Scottsdale, AZ 85253

Member w/Arthritis
951-2028 (H)
Term Expires: 1/19/98
Replaced: Reappointment

Dr. Francis Nardella
10599 N. Tatum Blvd, #F-150
Paradise Valley, AZ 85253

Professional Community
443-8400 (O)
Term Expired: 1/15/96
Replaced: Dr. Linda Karl

Lori Pearlmutter – Chair
Post Office Box 23803
Flagstaff, AZ 86002

Professional Community
526-5555, X-6613 (H) / 773-2125 (O)
Term Expires: 1/20/97
Replaced: Reappointment

Gail Kershner Riggs
3011 N. Palomino Park Loop
Tucson, AZ 85712

Member w/Arthritis
321-0692 (H) / 6266854 (O)
Term Expires: 1/19/98
Replaced: Reappointment

Dr. Barry Sauer
1800 E. Van Buren
Phoenix, AZ 85006

Advisory Member -
Harrington Research Center
254-0377 (O)

**ADVISORY COUNCIL ON ARTHRITIS & MUSCULOSKELETAL DISEASES
PAGE THREE**

Noreen Shcolnik
1789 W. Jefferson, #930A
Phoenix, AZ 85007

**Advisory Member-Dept of
Economic Security Rep**
542-3332 (O)

Dr. David Wayne Smith
c/o Arthritis Foundation
6464 E. Grant
Tucson, AZ 85715

Professional Member
290-9090 (O) / 529-0155 (H)
Term Expires: 1/20/97
621-9118 - FAX
Replaced: Reappointment

Dr. John Szivek
Arizona Health Sciences Center
1501 N. Campbell
Tucson, AZ 85724-5064

Public Member
626-6094 (O)
Term Expires: 1/19/98
Replaced: Linda Brickman

Carol Wilson
8815 East Snyder
Tucson, AZ 85747

Parent of Child w/Arthritis
290-9090 (H)
Term Expires: 1/19/98
Replaced: Kathleen Acciaioli

Kelly Wyland
3935 Tanyuri Drive
Tucson, AZ 85715

Person w/Arthritis
722-0940 (H)
Term Expire: 1/18/99
Replaced: Beverly Bulla

David E. Yocum, M.D.
Health Sciences Ctr, Rm 6409
1501 N. Campbell Avenue
Tucson, AZ 85724

**Adv Member-Rheumatology
Dept - Univ of AZ**
626-6041 (O)
Replaced: Dr. Eric Gall

Vincent Kelly
DES-RSA
1789 W. Jefferson, 930A
Phoenix, AZ 85007

Council Liaison
542-2595 (O)

**THE GOVERNOR'S COUNCIL ON ARTHRITIS
AND MUSCULOSKELETAL DISEASES**



***INVITES YOU TO A FREE PUBLIC LECTURE ON
"THE ROLE OF INFECTION IN ARTHRITIS"***

*The Arizona Inn
2202 East Elm
Tucson, Arizona
Tuesday, March 19, 1996
7:30 - 8:30 P.M.
(Cocktail hour and dinner
from 6 - 7:30 P.M. optional.)*

*The Harrington Arthritis Research Center
300 North 18th Street
Phoenix, Arizona
Thursday, March 21, 1996
2:00 - 4:00 P.M.
(Governor's Council on Arthritis and
Musculoskeletal Diseases to follow.)*

**A PUBLIC LECTURE BY
DR. GAIL CASSEL
CHAIR OF THE DEPARTMENT OF MICROBIOLOGY
UNIVERSITY OF ALABAMA**

ARIZONA DEPARTMENT OF HEALTH SERVICES
OFFICE OF DISABILITY PREVENTION

PROJECT: ASSESS THE PREVALENCE AND IMPACT OF FUNCTIONAL
LIMITATIONS IN THE STATE

TARGET DISABILITY GROUP: ARTHRITIS

According to Disability in America arthritis is the second most prevalent chronic condition across all ages and the first most prevalent for the elderly population with almost half reporting this conditions.¹ A recent study utilizing the Behavioral Risk Factor Surveillance System (BRFSS) within the state of Arizona estimated that a little over 13% of those reporting arthritis indicated that they experienced activity limitation every day or almost every day.² Utilizing the Model for the Prevention of Secondary Conditions associated with a primary disabling condition, it is proposed that the Office of Disability Prevention in collaboration with the Governor's Council on Arthritis and Musculoskeletal Diseases and the University of Arizona will develop a disability prevention profile for Arizona citizens reporting the potentially disabling condition of arthritis. Consistent with the disability model, the Council believes that impairment from arthritis does not necessarily lead to disability, and that the provision of early and appropriate intervention may prevent impairment from progressing to functional limitation, and disability.

A survey instrument will be developed through a contract with the University of Arizona. This survey would use questions consistent with national surveys as well as additional questions based on the Model for the Prevention of Secondary Conditions. It is anticipated that the survey would also include questions relative to (1) prescribed exercise, medications, and other modalities in the treatment of arthritis patients; (2) degree of compliance with the prescribed activities; (3) and risk factors associated with non-compliance. In addition, demographic data and quality of life measures would be utilized for appropriate placement within the model.

An implementation and evaluation plan would be developed through the contracting agency with input from the Council which includes a number of physicians and allied health professionals with backgrounds in research. Additional steps include the development of the conceptual framework for the disability prevention profile, pilot of the survey instrument, analysis of results and construction of the disability prevention profile for those with the primary disabling condition of arthritis. Analysis of the data will provide information regarding correlates of and

risk factors for the various components of the disability process - impairment, functional limitation, and disability. These results may lead to appropriate management of persons with arthritis in order to prevent disablement.

¹ Institute of Medicine. Committee on a National Agenda for Prevention of Disabilities. Disability in America: toward a national agenda for prevention. Andrew M. Pope and Alvin R. Tarlov, eds Institute of Medicine.

²CDC. Prevalence of arthritis-Arizona, Missouri, Ohio, 1991-1992. MMWR 1994;42:305-9.

ESTIMATES FOR 1996

AREA: ARIZONA

DES POP. ESTIM.: 4,297,787

1996 Population by agegroup: 1,149,574 1,708,611 832,497 340,974 266,131

ESTIMATED NUMBER OF AREA RESIDENTS WHO SELF-IDENTIFY AS HAVING SELECTED CHRONIC CONDITIONS. (DERIVED FROM NHIS* ESTIMATES)

CONDITION	TOTAL	AGE<18	18-44	45-64	65-74	75+
ARTHRITIS	606,367	2,759	92,436	216,366	151,495	143,312
VISUAL IMPAIRMENT	158,755	11,956	52,283	40,709	24,107	29,700
HEARING IMPAIRMENT	431,626	17,244	87,823	128,371	87,664	110,524
PARALYSIS, EXTREMITY	26,623	3,794	4,101	6,826	4,876	7,026
BACK DEFORM. OR IMPA	319,911	13,795	155,825	89,077	30,449	30,765
DIABETES	134,624	1,494	19,649	46,620	38,837	28,024
EPILEPSY	18,885	3,104	9,226	4,662	1,228	665
MIGRAINE	177,560	15,289	106,617	42,208	9,002	4,444
ISCHEMIC HEART DISEA	152,724	0	7,860	50,949	44,974	48,941
HYPERTENTSION	499,596	1,265	92,948	188,477	123,228	93,678
CEREBROVASCULAR DIS	62,231	230	1,879	14,402	22,300	23,420
HARDENING OF ARTERIE	43,864	0	1,196	10,323	13,503	18,842
VARICOSE VEINS	128,622	460	40,665	43,956	21,106	22,435
HEMORRHOIDS	164,798	230	68,686	59,274	19,470	17,139
CHRONIC BRONCHITIS	232,179	61,617	80,305	48,535	26,766	14,957
ASTHMA	210,984	72,883	76,717	37,462	14,901	9,022
HAY FEVER	434,692	82,080	217,848	84,582	28,812	21,370
CHRONIC SINUSITIS	624,330	79,665	292,343	155,927	53,840	42,554
EMPHYSEMA	35,788	0	2,050	12,487	10,366	10,885
MULTIPLE SCLEROSIS	3,574	0	1196	1831	307	240

*NHIS: National Health Interview Survey, 1992; conducted by the CDC, National Center for Health Statistics. This is a survey of the US population.

Source: Arizona Dept of Health Svcs; Chronic Disease Epidemiology. 14-Nov-95

ESTIMATES FOR 1996

AREA: MARICOPA

DES POP. ESTIM.: 2,493,607

1996 Population by agegroup: 660,083 1,024,333 481,068 177,811 150,312

ESTIMATED NUMBER OF AREA RESIDENTS WHO SELF-IDENTIFY AS HAVING SELECTED
CHRONIC CONDITIONS. (DERIVED FROM NHIS* ESTIMATES)

CONDITION	TOTAL	AGE<18	18-44	45-64	65-74	75+
ARTHRITIS	341,975	1,584	55,416	125,030	79,001	80,943
VISUAL IMPAIRMENT	91,080	6,865	31,345	23,524	12,571	16,775
HEARING IMPAIRMENT	244,872	9,901	52,651	74,181	45,715	62,425
PARALYSIS, EXTREMITY	15,092	2,178	2,458	3,945	2,543	3,968
BACK DEFORM. OR IMPA	186,069	7,921	93,419	51,474	15,879	17,376
DIABETES	75,658	858	11,780	26,940	20,253	15,828
EPILEPSY	11,024	1,782	5,531	2,694	640	376
MIGRAINE	104,292	8,779	63,918	24,390	4,694	2,510
ISCHEMIC HEART DISEA	85,249	0	4,712	29,441	23,453	27,642
HYPERTENSION	282,534	726	55,724	108,914	64,261	52,910
CEREBROVASCULAR DIS	34,438	132	1,127	8,322	11,629	13,227
HARDENING OF ARTERIE	24,366	0	717	5,965	7,041	10,642
VARICOSE VEINS	73,721	264	24,379	25,400	11,007	12,671
HEMORRHOIDS	95,395	132	41,178	34,252	10,153	9,680
CHRONIC BRONCHITIS	133,976	35,380	48,144	28,046	13,958	8,448
ASTHMA	122,356	41,849	45,993	21,648	7,770	5,096
COLD AND FLU	253,704	47,130	130,602	48,877	15,025	12,070
CHRONIC SINUSITIS	363,222	45,744	175,263	90,104	28,076	24,035
EMPHYSEMA	19,998	0	1,229	7,216	5,405	6,148
MULTIPLE SCLEROSIS	2,071	0	717	1058	160	135

*NHIS: National Health Interview Survey, 1992; conducted by the CDC, National Center for Health Statistics. This is a survey of the US population.

Source: Arizona Dept of Health Svcs; Chronic Disease Epidemiology. 14-Nov-95

ESTIMATES FOR 1996

AREA: SANTA CRUZ

DES POP. ESTIM.: 33,907

1996 Population by agegroup: 11,737 12,332 6,033 2,212 1,593

ESTIMATED NUMBER OF AREA RESIDENTS WHO SELF-IDENTIFY AS HAVING SELECTED CHRONIC CONDITIONS. (DERIVED FROM NHIS* ESTIMATES)

CONDITION	TOTAL	AGE<18	18-44	45-64	65-74	75+
ARTERITIS	4,104	28	667	1,568	983	858
VISUAL IMPAIRMENT	1,129	122	377	295	156	178
HEARING IMPAIRMENT	2,970	176	634	930	569	662
PARALYSIS, EXTREMITY	191	39	30	49	32	42
BACK DEFORM. OR IMPA	2,293	141	1,125	646	198	184
DIABETES	915	15	142	338	252	168
EPILEPSY	144	32	67	34	8	4
MIGRAINE	1,316	156	769	306	58	27
ISCHEMIC HEART DISEA	1,011	0	57	369	292	293
HYPERTENSION	3,410	13	671	1,366	799	561
CEREBROVASCULAR DIS	405	2	14	104	145	140
HARDENING OF ARTERIE	284	0	9	75	88	113
VARICOSE VEINS	888	5	293	319	137	134
HEMORRHOIDS	1,157	2	496	430	126	103
CHRONIC BRONCHITIS	1,824	629	580	352	174	90
ASTHMA	1,720	744	554	271	97	54
HAY FEVER	3,338	838	1,572	613	187	128
CHRONIC SINUSITIS	4,657	813	2,110	1,130	349	255
EMPHYSEMA	238	0	15	90	67	65
MULTIPLE SCLEROSIS	25	0	9	13	2	1

*NHIS: National Health Interview Survey, 1992; conducted by the CDC, National Center for Health Statistics. This is a survey of the US population.

Source: Arizona Dept of Health Svcs; Chronic Disease Epidemiology. 14-Nov-95



ARTHRITIS

The Problem

The Status

The Plan

Missouri Arthritis Advisory Board

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Missouri Department of Health

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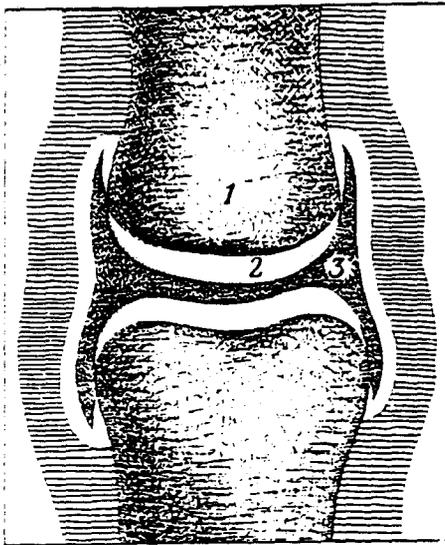
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ARTHRITIS — THE PROBLEM, THE STATUS, THE PLAN

I. INTRODUCTION



Normal Joint

1. Bone
2. Cartilage
3. Joint Fluid

Arthritis is one of Missouri's most common chronic disorders, affecting as many as 1.2 million of its residents. The term "arthritis" applies to more than 100 different conditions of unknown or varied causes. Joint involvement is the most characteristic aspect of arthritis but various forms can also result in such problems as kidney disease, blindness and premature death.

The Missouri Arthritis Program was created by the 82nd General Assembly in 1984 when it passed HB1028. Regional Arthritis Centers were established in seven regions of the state through contracts with existing health care institutions. These centers provide services in the areas of professional, patient and public education to emphasize the importance of early, accurate diagnosis and discourage the use of unapproved and ineffective diagnostic and treatment methods. It is crucial that persons with arthritis receive early diagnosis and proper treatment in order to minimize disability and enjoy productive lives.

It has been three years since the Missouri Arthritis Program was established. At this time it is wise to review:

- the magnitude of the disease and the causes;
- the factors that increase the risk for this disease and its problems;
- the programs and activities that have been directed toward these problems;
- the strengths and weaknesses of program efforts; and
- recommendations for future plans.

This report will summarize the review of these arthritis issues.

II. HOW MANY PEOPLE HAVE ARTHRITIS

The glossary (in this document) defines the more common types of arthritis. Approximately one out of three persons over 18 years of age reported having arthritis in this state when a telephone survey of 2,500 households was conducted in 1987 by the Arthritis Program and the University of Missouri. Reported prevalence was higher in women (38%) and lower in males (28%). It is also more common in older population groups (68% among those over 65) and lower in younger age groups (12% in 18-34 year-olds). When the survey results are extrapolated to the entire population, an estimated 1,260,000 Missourians may have arthritis.

The survey results compare favorably to national prevalence studies of arthritis and musculoskeletal impairments. The Missouri prevalence of 33.6% is slightly higher than the national estimate of 32.6%.¹ This could be explained by the higher percentage of older persons in Missouri, which ranks sixth in the nation in percentage of population (14%) over 65. Since arthritis occurs much more frequently in older adults this could account for a greater number of Missourians with arthritis.

Arthritis occurs more frequently than other chronic diseases. Table 1 shows prevalence estimates of several chronic diseases in Missourians.

Table 1
Prevalence Estimates of Selected Chronic Diseases in Missouri

	<u>Prevalence</u>
Arthritis ¹	34%
At risk for coronary heart disease ²	22%
High blood pressure ³	18%
Diabetes ⁴	6%

¹ Arthritis Program Survey, Missouri Department of Health, 1987

² High serum cholesterol levels, NHANES II estimates, 1986

³ Behavioral Risk Factor Survey, Missouri Department of Health, 1986

⁴ NHANES II estimates, 1986

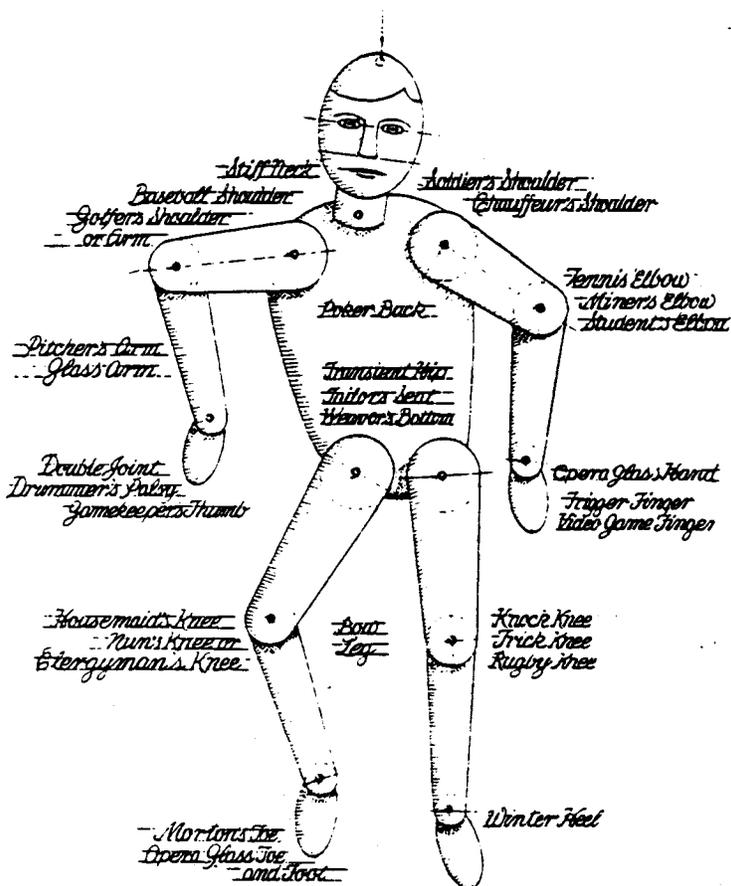
III. PROBLEMS DUE TO ARTHRITIS

While the amount of disability that the average patient with arthritis experiences is less than in the case of some other chronic diseases, the overall disability prevalence is highest because of the large number of persons affected by the disease. Arthritis is America's number one crippling disease. It has been estimated that \$14 billion is lost annually in wages and medical bills. Arthritis accounts for 500 million days of restricted activity and 26 million days lost from work. This disease is the leading cause of industrial absenteeism and, after heart disease, the second leading cause of disability payments.²

The category of arthropathies and related disorders was the eleventh leading principal diagnosis for hospitalizations in Missouri in 1983. There were more than 12,500 hospitalizations for treatment of these conditions during a one-year time period.³

A national survey reviewed the amount of disability caused by having a history of musculoskeletal symp-

BY ANY OTHER NAME,
IT'S STILL ARTHRITIS



toms. The type of disability by area of the body involved is reported in Table 2. Persons who reported involvement of all areas (back or neck and the upper and lower extremities) were most likely to report each disability outcome.¹

Table 2

Percentage of Respondents with History of Musculoskeletal Symptoms Reporting Specific Disabilities by Area of Body Involved¹

Area of Body Involved	Percentage Reporting		
	Moderate/Severe Activity Restriction	Change in Job Status	Five or More Days Lost from Work
Upper Extremity Lower Extremity, and Back/Neck	37.8	27.4	18.4
Upper and Lower Extremities	19.1	12.6	8.0
Upper Extremity and Back/Neck	20.0	16.5	7.4
Lower Extremity and Back/Neck	31.0	26.5	17.2
Upper Extremity Only	7.8	11.6	2.9
Lower Extremity Only	13.6	12.4	5.5
Back/Neck Only	17.8	16.3	14.2

This national review of disability also suggested an effect of social disadvantage on disability rates. These effects might be explained by a lack of financial and/or social resources with which to deal with the impairment. Having less than a high school education is associated with having had to change jobs because of a musculoskeletal condition and with having lost five or more days of work in the past year.¹ A study done by Yelin et al found that people with rheumatoid arthritis, who had unskilled jobs with strict work schedules were more likely to become unemployed than were people with rheumatoid arthritis who had white collar or professional occupations.⁴ It is proposed that this is due to the fact that low-paying nonskilled jobs may be

more difficult or impossible to perform in the presence of chronic musculoskeletal symptoms either because of the physical requirements of the job or because of inflexible work schedules.

Mortality rates among those with rheumatoid arthritis are higher than in the general population.⁵⁶ This has been attributed to the disease itself as well as associated complications of the respiratory tract and the increased incidence of general infections seen in those with rheumatoid arthritis.

IV. RISK FACTORS AND FACTORS INCREASING SEVERITY OF PROBLEMS

The most important risk factor for arthritis is age, which cannot be controlled. Arthritis is much more prevalent in older population groups. Other uncontrollable factors include:

Sex:

Various forms of arthritis are more prevalent among females than among males.⁷ Hormonal factors have been suggested. Some investigators have found that women who use oral contraceptives are at reduced risk of rheumatoid arthritis.⁸ Gout and ankylosing spondylitis occur more frequently in males.⁷

Race:

Whites and non-whites are affected with musculoskeletal impairments with almost equal frequency.¹ Ankylosing spondylitis occurs primarily in whites. Systematic lupus erythematosus has a higher incidence in blacks and Hispanics.⁷

Controllable risk factors identified for arthritis include:

Weight Status:

It has been suggested that obesity may aggravate the "wear and tear" on joints and increase risks for developing osteoarthritis.

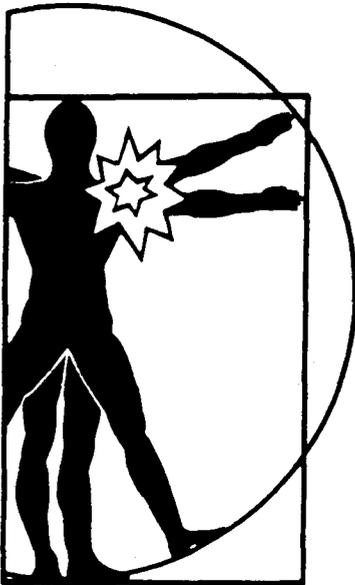
Occupation:

Prevalence rates have been reported to be somewhat elevated in certain occupational groups (e.g., coal miners and dock workers) but patterns are not consistent.

Other Factors:

Knowing which risk factors increase the likelihood of developing arthritis and musculoskeletal impairments is very useful in assessing health care needs and planning interventions that are targeted to meet those needs. In addition, it is helpful to look at behaviors and other problems that might increase the severity of complications in those who have arthritis. Programs can be directed at minimizing those problems.

Through the state arthritis survey it was learned that 84% of persons with arthritis stated their symptoms would have to be moderate to severe before they would seek treatment even though 64% said they believed arthritis was a serious disease. This is unfortunate because the progression of the disease can be retarded and symptoms ameliorated by routine treatments.



There were also some misperceptions among people with arthritis regarding the causes and appropriate treatment for the disease. These types of misperceptions can leave Missourians susceptible to try unproven remedies which not only waste the consumer's resources but also may delay treatment needed to offset preventable complications and disability. Useless or unproven remedies that persons with arthritis reported using included copper bracelets, bee venom and DMSO.

The survey also revealed that the general public is seriously misinformed regarding the causes of arthritis; the nature and types of available, effective treatments; and sources for optimal care. These issues must be addressed as part of a comprehensive arthritis program in order to prevent complications due to lack of information.

V. MISSOURI ARTHRITIS PROGRAM

Efforts Began, Task Force Appointed

Missouri began working toward a state arthritis plan in 1976 when a broad spectrum of people interested in arthritis formed a coalition to address state arthritis needs. The Missouri Task Force on Arthritis was officially appointed by the Missouri Board of Health in 1977 and charged to survey and assess arthritis needs and formulate recommendations for using state resources to combat arthritis.

Hearings Held, Recommendations Issued

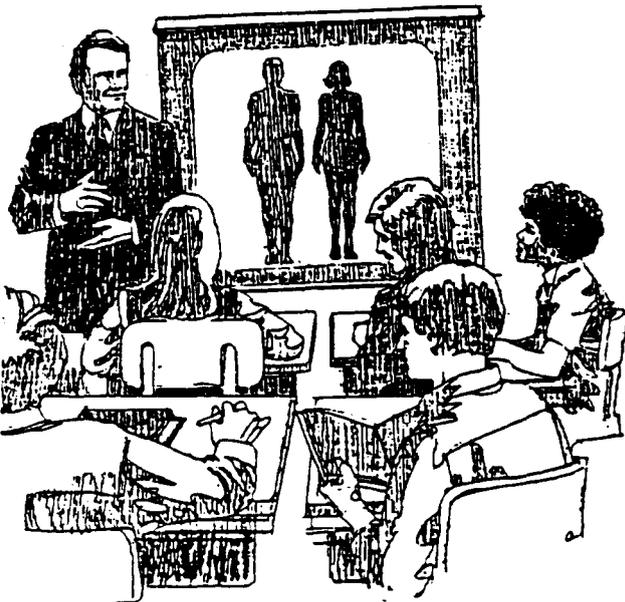
Work groups were formed and voluminous amounts of data were collected and analyzed. In 1979, eight public hearings were held throughout the state with more than 800 individuals participating and testimony received from a wide range of witnesses. The testimony was compiled and studied by the Task Force and a consensus of recommendations emerged:

- Establish a statewide network of regional arthritis centers for diagnostic, treatment and education services;
- Offer a continuing education program for physicians and allied health professionals;
- Train and recruit more rheumatologists for outlying areas lacking this specialty;
- Improve public education; and
- Increase research efforts.

A three volume report with the State Arthritis Plan and background data was printed in 1980.

Legislation Enacted

An arthritis bill, encompassing the State Arthritis Plan's recommendations, was first submitted to the Missouri General Assembly in 1980. After four years of extensive legislative efforts, House Bill 1028 was enacted and signed into law in 1984.



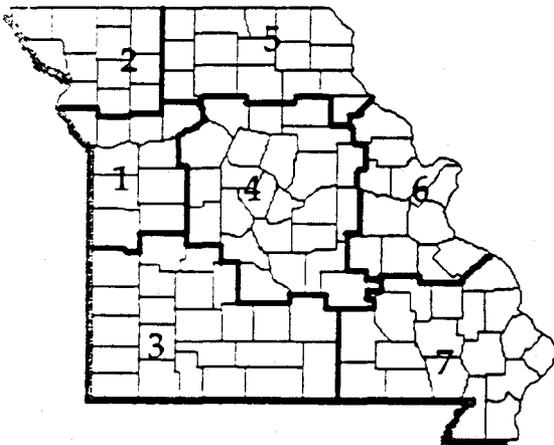
Missouri Arthritis Program Begun

The legislation gave the Department of Health the authority to establish a network of seven regional arthritis centers and to appoint two advisory bodies. A 25-member Missouri Arthritis Advisory Board was formed and charged to make recommendations to the Department of Health on the statewide arthritis plan and assist with issuing guidelines for the services provided by the Regional Arthritis Centers. A separate Program Review Committee was created with 15 members to ensure meritorious selection of the regional centers. The program is administered by the Bureau of Chronic Diseases in the Missouri Department of Health.

In the fall of 1985 eight Regional Arthritis Centers were selected from applications from health care institutions and funds were awarded. The eight designated centers are listed below.

Regional Arthritis Centers

- 1 Greater Kansas City Area
St. Luke's Hospital-Kansas City
- 2 Northwest
Heartland Health Systems-St. Joseph
- 3 Southwest
St. John's Hospital-Springfield
- 4 Central
Health Sciences Center
University of Missouri-Columbia
- 5 Northeast
Kirksville College of Osteopathic
Medicine-Kirksville
- 6 Greater St. Louis Area (2 centers)
Washington University-St. Louis
St. Louis University-St. Louis
- 7 Southeast
St. Francis/Southeast Hospital-
Cape Girardeau



Arthritis Center
Regions

First Year Activities

Much effort was devoted during the first year (1985-1986) to establish the network of regional centers. The centers began on a full-force basis with an impressive list of first year accomplishments:

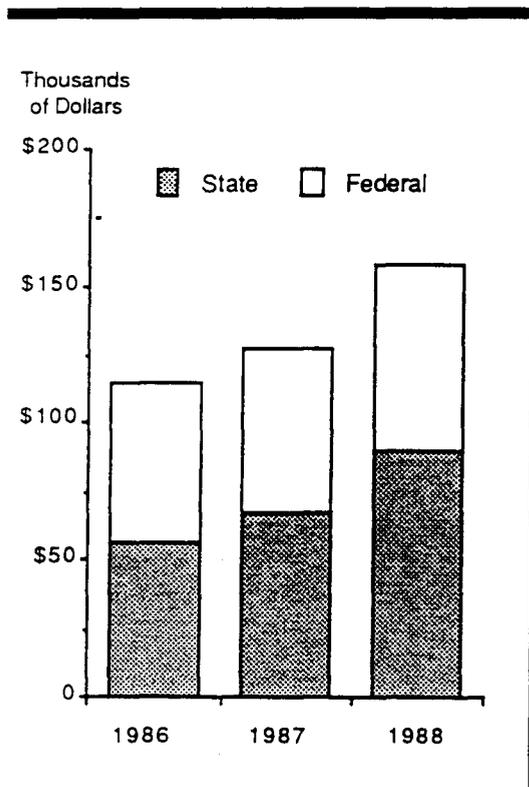
- Education of 600 health professionals;
- Contact with more than 4,000 persons, with 1,100 attending public education sessions; and
- Improved care and education for more than 500 persons with arthritis attending self-help courses.

Second Year Advances

Accomplishments the second year (1986-87) were even more impressive than those seen the first year:

- Education of 2,000 health professionals;
- Education of 3,500 at public sessions;
- Specially tailored exercise programs and courses for more than 500 persons with arthritis; and
- Survey of 2,500 households to identify attitudes, knowledge and beliefs among the general public about arthritis.

**Arthritis Program Funding
by Source 1986 - 1988**



Fiscal Summary

Funding for the Missouri Arthritis Program first became available in Fiscal Year 1986 which began Oct. 1, 1985. During that year, a total of \$56,032 state general revenue was made available. This was augmented with \$59,798 of federal preventive block grant money for a total budget of \$115,830. In Fiscal Year 1987 this amount was increased slightly to \$125,830 (\$65,755 in state general revenue and \$60,075 in federal block grant monies).

An increase in preventive block grant appropriations will increase total funding for the Arthritis Program to \$153,119 for fiscal year 1988. This breaks down to \$90,075 federal and \$63,044 state revenue.

VI. STRENGTHS AND WEAKNESSES

With approximately one-third of Missourians affected by arthritis it is wise to address this problem through a public health chronic disease program. Program efforts, primarily public, patient and professional education, have been directed toward helping individuals minimize the disease impact.

In the first two years of operation a network of regional arthritis centers has been implemented. The network serves as an excellent means to refer patients with arthritis to a diagnostic and treatment center near their home. Educational outreach efforts have been very effective in improving the information available in the communities within each of the regions. A wide range of programs and services have been offered. Examples of these include:

- self-help stores that make special aides available for persons with physical impairments;
- community aquatics courses for persons with arthritis with resourceful use of local facilities;
- community education offered through adult education classes, speakers bureaus for service organizations and local health fairs; and
- self-help courses taught in Spanish for the Kansas City hispanic population.

Efforts within each of the regions have involved the collaboration of a number of people and agencies. Private physicians, the Arthritis Foundation, and community hospitals are some of the forces that have joined to maximize the community impact of the program.

Modest funding has limited the types and extent of programs offered by the regional centers. More attention to evaluation of program activities would enable the state program to identify efforts that are most effective in impacting the problems of arthritis. Additional funding would allow the implementation of programs designed and directed toward groups that

are at higher risk for arthritis problems. Activities to date have necessarily had to focus on establishing the centers and gaining recognition for them. At this stage of the program it is time to select activities that most effectively serve the arthritis community.

VII. RECOMMENDATIONS

WHAT YOU DON'T KNOW ABOUT ARTHRITIS CAN HURT YOU

Swelling in one or more joints
Early morning stiffness
Recurring pain or tenderness in any joints
Inability to move a joint normally
Obvious redness and warmth in a joint
Unexplained weight loss, fever or weakness combined with joint pain
Symptoms like these persisting for more than two weeks.

If you have these warning signs, consult your family physician or rheumatologist. For more information about arthritis, contact your nearest chapter of the Arthritis Foundation.

Public health programs have traditionally directed efforts toward primary prevention. The nature and course of arthritis, however, does not warrant the traditional approach of using screening measures to identify asymptomatic individuals. Programs instead must be directed toward secondary prevention, ensuring proper diagnosis and treatment to avoid or lessen the complications of arthritis.

The following recommendations are made for the Missouri Arthritis Program.

- Continue public, patient and professional education efforts 1) to decrease the misperceptions the public has regarding arthritis and its treatment and 2) to increase the public's knowledge of the early symptoms of the disease and the importance of proper diagnosis and early treatment.
- Identify and address problems that interfere with patients receiving optimal care. These problems include inadequate health insurance, incorrect diagnosis and poor adherence to prescribed treatment.
- Offer targeted and innovative interventions directed at persons at higher risk for arthritis or persons having arthritis. Examples of such programs include:
 - ✓ Special exercise and weight control programs designed for older women in the community.

- ✓ Home consultation on environmental changes and use of special aides to enhance independent living.
- ✓ Worksite programs to minimize work days missed and provide consultation on job adaptation.
- Improve coordination of Regional Arthritis Centers with the Arthritis Foundation to ensure complimentary rather than duplicative services.
- Increase funding to support expanded program efforts.

Arthritis and disorders of the musculoskeletal system are among the most common health problems that people face. They affect all age groups and are associated with a great deal of disability, impairment and handicap. There are a wide variety of conditions included under the term arthritis and they range in severity from relatively minor aches and pains to chronic disabling conditions such as rheumatoid arthritis. Although arthritis is occasionally fatal, the main impact is on quality of life and on economic productivity.⁹

The Missouri Arthritis Program has begun to address arthritis issues and should continue its efforts to impact the problems associated with this disease. A broad spectrum of support needs to be maintained and strengthened for these efforts to continue.