# ARTHRITIS ACTION PLAN



ILLINOIS DEPARTMENT OF PUBLIC

HEALTH

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Arthritis and related conditions currently affect nearly 43 million Americans, making it one of the most prevalent diseases in the United States. By 2020, as the baby boom generation ages, an estimated 60 million Americans will be affected by arthritis. Arthritis is the leading cause of disability in the United States, and although cost-effective interventions are available, they are currently underused. The economic burden of arthritis is substantial, costing the U.S. health care system nearly \$65 billion annually. Arthritis affects the quality of life of the person who experiences this painful condition, as well as their family members and caregivers.

Beginning in 1999, more than 55 organizations joined the Illinois Department of Public Health in a comprehensive effort to address the burden of this disease in Illinois. It is estimated that 2.41 million, or 26.4 percent of Illinois citizens live with some form of arthritis. The Illinois Arthritis Action Plan provides a framework for prevention and education efforts in Illinois. The plan represents a shift away from the traditional approach of treating individuals with arthritis to a public health approach that emphasizes—

- identifying arthritis at its earliest stage and initiating prompt, appropriate management;
- reducing the consequences of arthritis once it has developed; and
- preventing arthritis whenever possible.

The Department extends its appreciation to those who served on the planning committee and contributed their time and expertise to this effort. The Illinois Arthritis Action Plan challenges communities, public health professionals and health care providers to educate, inform and motivate the public in maximizing resources to reduce the burden of arthritis in this state. Together, we can ensure a better quality of life for all Illinoisans with arthritis.

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Director of Public Health

### **EXECUTIVE SUMMARY**

#### **MISSION STATEMENT**

The mission of the Illinois Arthritis Initiative is improving the quality of life for Illinoisans affected by arthritis.

#### VISION STATEMENT

The state of Illinois, consistent with objectives identified in the *National Arthritis Action Plan*, has the commitment, capacity and resources to create surveillance mechanisms, interventions and policies to achieve the following:

- promote early diagnosis, treatment and appropriate management of arthritis to ensure the highest quality of life for people with the disease;
- prevent arthritis through recognition and modification of risk factors;
- minimize preventable pain and disability due to arthritis;
- increase public awareness of arthritis as the leading cause of disability;
- support persons with arthritis in accessing the resources they need to cope with their disease; and
- ensure that persons with arthritis receive the family, peer, caregiver and community support they need to facilitate successful self-management.

Arthritis includes more than 120 rheumatic diseases and conditions affecting joints, the surrounding tissues and other connective tissues. It is the leading cause of disability among persons 15 years of age and older in the United States and has sharp economic impacts. It also limits daily activity for more than 7 million citizens, thereby having a significant effect on quality of life, not only for the for the person with the disease, but also for family members and caregivers.

#### THE FACTS

- Approximately 2.41 million, or 26.4 percent of **Illinois** adults suffer from symptoms related to arthritis or chronic joint disease.
- More than one-third (37.4 percent) of those with arthritis in Illinois reported activity limitations.

#### THE CHALLENGE

Illinois' diversity creates unique challenges for addressing the burden of arthritis. More than 23.3 percent of the state's population resides in the city of Chicago; 83 of the 102 counties are designated rural areas; and there is enormous statewide racial and ethnic diversity. The Illinois Department of Public Health (IDPH), through its Arthritis Partnership, is applying a *public health approach* to addressing arthritis. The focus of this approach will be broad and encompass whole population groups, utilizing the concepts of primary, secondary and tertiary prevention. The challenge is to ensure the delivery of effective interventions to persons in Illinois with greatest risk of arthritis and its complications. *Healthy People 2010* and the *National Arthritis Action Plan* will be used to support and help to guide the state's efforts.

This plan represents the collaborative efforts of more than 55 agencies, organizations, academic institutions, professional groups and persons with arthritis who are dedicated to reducing the burden of the disease in Illinois.

#### THE PLAN

Although IDPH is concerned with all rheumatic diseases and conditions, the major focus will be on osteoarthritis, rheumatoid arthritis, fibromyalgia, systemic lupus erythematosus, gout and juvenile rheumatoid arthritis. Target populations include persons affected by arthritis (those with the disease or condition, family members, caregivers, etc.), with a special emphasis on minority groups, rural populations, uninsured and under-insured, and the under-served.

Following are the plan's four major focus areas and supporting objectives to be achieved by the year 2005:

#### Surveillance and Data

By 2005, implement a comprehensive Illinois arthritis surveillance system.

#### **Public Education**

By 2005, improve access to education opportunities derived from evidence-based strategies for the public and persons affected by arthritis.

**Professional Education and Health Care Systems** By 2005, improve arthritis knowledge, attitudes and referral practices of primary health care professionals.

#### **Public Policy and Infrastructure**

By 2005, increase appropriate resources and funding for statewide and local arthritis disability prevention programs.

This Illinois Arthritis Action Plan outlines strategies and actions to achieve these objectives. It is hoped that the plan will be instrumental in decreasing the burden of arthritis and increasing the quality of life for those affected by the disease in Illinois.

# THE ILLINOIS ARTHRITIS INITIATIVE

he National Arthritis Act of 1974 authorized substantial expansion of research, training, public education and treatment concerning the disease. It recommended establishment of an Institute of Arthritis within the National Institutes of Health, an arthritis data bank,

comprehensive arthritis centers and development of a long-range plan to address arthritis across the nation. In 1999, the last of these four major recommendations was completed with the publication of the *National Arthritis Action Plan* (NAAP). Subsequent funding from the U.S. Centers for Disease Control and Prevention (CDC) has helped states to identify the burden of arthritis in their populations and to implement proven interventions to reduce disability and improve the quality of life of people with arthritis.

Recognizing the burden of rheumatic diseases in the state, the Illinois Department of Public Health (IDPH) actively pursued funding to develop a plan for addressing arthritis control. In 1999, Illinois became one of eight core states designated by the CDC to receive arthritis initiative grant funding.

The initial and continuing focus of the Illinois Arthritis Initiative (IAI), has been to identify, develop and utilize statewide capacity in designing a comprehensive arthritis program. In 1999, the Illinois Arthritis Partnership was formed. This group consists of approximately 75 members representing more than 55 agencies and organizations. The partnership's multidisciplinary perspective contributes greatly to its task of reducing the burden of rheumatic diseases and conditions in Illinois.

Another major focus of the initiative was creating four work groups to address specific issues of arthritis concern: Surveillance and Data, Public Education, Professional Education/Health Care Systems, and Public Policy and Infrastructure. The dynamic nature of the partnership and work group structure necessitates continual recruitment and expansion of group memberships to ensure that needs of the initiative are met. An additional focus was the beginning of a comprehensive arthritis surveillance system. A data team continuously strives to access, assess and interpret available Illinois arthritis data sources, and to identify additional data sources. An *Illinois Arthritis Data Report* was developed in 2002 to document the current burden of arthritis in Illinois.

Arising from two years of planning, IDPH and the partnership are pleased to share the *Illinois Arthritis Action Plan.* This plan outlines state-specific objectives for arthritis activities for the years 2000 through 2005. The NAAP and *"Healthy People 2010"* (HP2010) objectives **(Appendix A)**, which are designed to increase quality and years of healthy life and to eliminate health disparities, were incorporated into the plan. This ensures that statewide efforts are appropriately tied to national concerns.

The plan provides a useful guide for state and local providers, persons affected by arthritis and their families, care givers, medical care providers, policy makers and the general public to better understand ongoing IAI efforts to reduce the impact of arthritis. Because of the public health based approach, the plan provides a useful tool for the development of state and local efforts in arthritis awareness, diagnosis, treatment, prevention and surveillance. Finally, the plan can be used as a supplement to existing arthritis programs.



# A N O V E R V I E W

This arthritis overview provides a foundation for the content of the *Illinois Arthritis Action Plan*. It begins by identifying and dispelling the three most common arthritis myths, offers a definition of arthritis chosen by the IAI, and addresses prevention and treatment issues.

#### **ARTHRITIS MYTHS**

The burden of arthritis for Illinois, as well as for the nation, is compounded by prevailing myths about the disease. It has long been recognized that myths about arthritis hinder people from seeking early diagnosis, treatment and appropriate management. There are three common myths about arthritis:

#### "Arthritis is an old person's disease."

**Fact:** People of all ages are afflicted with arthritis; in fact, 60 percent of those with the disease are younger than age 65. There are more than 300,000 children in the U.S. with arthritis, with juvenile rheumatoid arthritis being one of the most common chronic illnesses of childhood.

#### "Arthritis is just a normal part of aging."

**Fact:** If this were true, most older adults—and no children— would have arthritis. Half of those age 65 and older do **not** have symptomatic arthritis.

### "There is no cure for most forms of arthritis."

**Fact:** Although no "magic cure" for all types of arthritis exists, research shows that early diagnosis and appropriate management can help reduce the pain, improve function and commonly prevent further joint destruction associated with many types of arthritis.

#### **DEFINITION OF ARTHRITIS**

The IAI defines "arthritis" as the more than 120 rheumatic diseases and conditions affecting joints, the surrounding tissues and other connective tissues. Arthritis may cause pain, stiffness, and swelling not just in joints but other supporting structures of the body such as muscles, tendons, ligaments and bones. Some rheumatic diseases are also autoimmune disorders and affect other parts of the body, including internal organs.

Examples of rheumatic diseases include the following: osteoarthritis, rheumatoid arthritis, fibromyalgia, systemic lupus erythematosus, juvenile rheumatoid arthritis, and gout. These six diseases, listed in order of national estimated prevalence rates, provide the focus for the *Illinois Arthritis Action Plan*.

**Osteoarthritis** is the most common type of arthritis and affects an estimated 20.7 million adults in this country. It primarily impacts cartilage (the tissue that cushions the ends of bones within joints) and can lead to pain, limited motion, deformity and loss of function. In its most severe form, untreated osteoarthritis can result in severe joint damage and disability.

**Rheumatoid arthritis** is an inflammatory disease of the synovium (lining of the joint) that results in pain, stiffness, swelling, deformity and loss of function of the joint. In the most severe form, rheumatoid arthritis can cause joint symptoms plus fatigue, fever and a general sense of illness for many years, resulting in severe joint damage and disability. Less common than osteoarthritis, it affects 2.1 million persons in the United States.

**Fibromyalgia** is a chronic disorder that causes pain and stiffness throughout the tissues that support and move the bones and joints. Pain and localized tender points occur in the muscles and tendons, especially those of the neck, spine, shoulders and hips. Other common symptoms are widespread pain, fatigue and sleep disturbance. Fibromyalgia affects approximately 5 million people in the United States.

# A N O V E R V I E W

**Lupus** can be classified as one of four types: discoid lupus erythematosus, drug-induced systemic lupus erythematosus, neonatal lupus and systemic lupus erythematosus (SLE). SLE is a chronic, inflammatory, multisystem disorder of the immune system. According to the American College of Rheumatology, the prevalence of SLE is 40-50 cases per 100,000 population. Because it is the most common type of lupus (more than 70 percent of all diagnosed lupus is SLE), the Illinois Arthritis Initiative will focus on SLE.

**Gout** is a type of arthritis that causes sudden, severe attacks of pain, swelling, redness, warmth and tenderness in the joints. It results from deposits of needle-like crystals of uric acid, a byproduct of the breakdown of purines or waste products in the body, in connective tissue, joint spaces or both. These deposits lead to swelling, redness, heat, pain and stiffness in the joints. It usually affects the joint of the big toe but can occur in feet, ankles, knees, hands and wrists.

Gout accounts for about 5 percent of all cases of arthritis. According to the American College of Rheumatology, the prevalence rate for gout in all Americans is 840 cases per 100,000 persons.

Juvenile rheumatoid arthritis (JRA) is arthritis that causes joint inflammation and stiffness for more than six weeks in a child 16 years of age or younger. Children can develop almost all types of arthritis that affect adults, but JRA is the most common type of arthritis in young children. Nearly 300,000 children have arthritis with about 70,000 to 100,000 of these children having juvenile rheumatoid arthritis.

#### PREVENTION AND TREATMENT OF ARTHRITIS

While the science supporting prevention and treatment interventions for arthritis is relatively new, there is much known about who is at risk and about effective treatments for those with many forms of the disease. In general, although it is not a normal part of aging, the risk for arthritis increases with age. Women and those with certain genetic profiles also appear to be at greater risk for some forms of the disease. For example, it is known that lupus is more common among African Americans and Hispanics than among other racial groups. Moreover, most forms of the disease are characterized by certain modifiable risk factors. Using osteoarthritis of the knee as an example, the key risk factors appear to be obesity and prior knee injury. Prevention trials have not yet been performed.

There has been a recent explosion of arthritis-related treatment research that has led to many new and effective medical, surgical, rehabilitation and self-management techniques for arthritis. New **medications** include the COX-2 inhibiting non-steroidal anti-inflammatory drugs (NSAIDs), which can control pain and inflammation with much less risk of gastrointestinal bleeding compared to traditional NSAIDs. New biologic medications for the treatment of rheumatoid arthritis better control this disease's inflammation and prevent further joint destruction. Ongoing research is expected to yield even better treatments in the future.

**Total joint replacement** surgery has been the major means of treating the severe pain and preventing the disability of advanced hip, knee and shoulder arthritis. Technological and clinical advances allow for the resurfacing of these joints (which have lost cartilage due to arthritis) with durable metal and plastic. While most total joint replacements are performed on the elderly, they also have been successfully done in younger patients, including children. New areas of research include cartilage and chondrocyte (cartilage cell) transplant.

**Rehabilitation treatments,** such as exercises to improve muscle strength and aerobic conditioning, have been shown to be effective in decreasing the pain and reducing the functional limitation associated with arthritis. Studies clearly show that exercise is good for persons with arthritis, something that was not thought to be true in the past. Exercise regimens such as repetitive low weight lifting, vigorous walking programs and water exercise programs have all been shown to be beneficial. Current research is focused on finding ways to encourage healthy exercise behavior after physical therapy has concluded.

Perhaps the most important type of treatment that has been found to be effective for persons with arthritis is **self-management**. Self-management programs teach patients how to take control of their arthritis by acquiring the knowledge, skills and attitudes that empower them to make good decisions about pain relief, exercise behavior and problem solving. The combination of self-management with appropriate medical, surgical and rehabilitation treatment gives patients considerable hope that something CAN be done to help with the pain and disability of arthritis.

#### **ARTHRITIS PROJECTIONS**

The Behavioral Risk Factor Surveillance System (BRFSS) is a statewide survey of a representative random sample of Illinois adults who answer questions related to health status and behaviors that may lead to the development of chronic diseases. Surveillance system results for the first half of the year 2000 show that 26.4 percent of the adult population in Illinois (2,410,000 persons) is affected by arthritis or chronic joint symptoms. Of those, 8 percent felt some limitation in their activities because of joint symptoms, and 8.5 percent had been unable to do their usual activities (e.g., self-care, work, recreation, etc.) during the preceding 30 days because of arthritis pain. These data begin to put into focus the disability and financial burden faced by the people of Illinois who struggle with arthritis. It should be noted that these estimates leave out the very real impact on the people who care for persons with arthritis. The Illinois Arthritis Action Plan strives to recognize the burden that arthritis inflicts on caregivers; exploring their concerns is an integral part of the initiative. Another focus of the plan involves identifying and targeting populations with unmet needs with regard to arthritis. An understanding of the unique demographics of the state can begin to reveal these disparities.

#### **QUALITY OF LIFE**

Arthritis is a chronic disease that leaves many people feeling that they have received a lifetime sentence of disability and a limited quality of life. Persons with arthritis report far more days when their physical and mental health are not good compared to persons without arthritis. In addition, those with arthritis report many more days each month when their health keeps them from doing their usual activities compared to those without arthritis. For these analyses, the different age distributions of the group with arthritis and those without were taken into consideration.

#### MEAN NUMBER OF DAYS HEALTH AFFECTED IN A MONTH

DAYS PHYSICAL HEALTH NOT GOOD
With arthritis or chronic joint symptoms6.4
Without arthritis or chronic joint symptoms I.8
DAYS MENTAL HEALTH NOT GOOD
With arthritis or chronic joint symptoms
Without arthritis or chronic joint symptoms
DAYS HEALTH KEPT FROM DOING USUAL ACTIVITIES
With arthritis or chronic joint symptoms
Without arthritis or chronic joint symptoms I.9
MEAN NUMBER OF DAYS WITH ARTHRITIS PAIN
Adults with arthritis or chronic joint symptoms
PERCENTAGE OF ADULTS
With arthritis or chronic joint symptoms with activity limitations due to arthritis

Questions related specifically to arthritis were asked only of those who reported arthritis and chronic joint disease according to the definitions used in this report. Persons with arthritis report an average of 8.5 days each month during which they experience pain. More than one-third (37.4%) of those who met the definition for arthritis responded that the disease limits their activities.

A higher proportion of persons with arthritis report needing help with both routine and personal care compared to those without arthritis. These results held in analyses that considered the differences in age when comparing persons with and without arthritis.



#### SOURCE: 2000 Illinois Behavioral Risk Factor Surveillance System

#### Health and Health Behaviors

In general, a greater proportion of persons with arthritis perceived their health to be only "fair" or "poor" when compared to persons without arthritis. This difference takes into account that people with arthritis are older and, therefore, may be subject to other chronic conditions in addition to arthritis.

#### **NEED HELP WITH PERSONAL CARE**



SOURCE: 2000 Illinois Behavioral Risk Factor Surveillance System

#### **PERCEIVED HEALTH STATUS**



Surveillance System

#### ILLINOIS DEMOGRAPHICS AND TRENDS GENERAL POPULATION

Illinois is the fifth most populous state in this country. Its population is not spread equally around the state. During the last decade, the city of Chicago and seven surrounding counties witnessed a substantial increase in population at the expense of other areas of the state.

Eighty-three of Illinois' 102 counties are designated rural areas by the BRFSS, based on CDC criteria and endorsed by the state coordinator of the surveillance system. These criteria are population size, density and growth patterns. By 2004, there will be county-specific data pertaining to arthritis for each of the state's 102 counties.

Demographics demonstrate enormous statewide racial and ethnic diversity as well. The 2000 U.S. Census Bureau data regarding the IAI's chosen target groups shows that, racially, approximately 73.5 percent of the state's population is white and 15.1 percent African American. Ethnically, the state's population is 12.3 percent Hispanic or Latino. The following table provides a more complete racial/ethnic breakdown.

#### NEED HELP WITH ROUTINE CARE

RACE	POPULATION	PERCENT
Total	12,419,293	100.0
White Alone	9,125,471	73.5
Black or African American Alone	1,876,875	15.1
American Indian or Alaska Native Alone	31,006	0.2
Asian Alone	423,603	3.4
Native Hawaiian or other Pacifice Islander	4,610	0.0
Some Other Race Alone	722,712	5.8
Two or More Races	235,016	1.9
Hispanic or Latino (of any race)	1,530,262	12.3

SOURCE: U.S. Census Bureau, Illinois, 2000

Racial groups that may be differently affected by rheumatic diseases account for fully one-quarter of the state's population. This increase in racial diversity is expected to continue. Recent population projections indicate an increase of 8.6 percent in population. Much of this increase is due to immigration (a significant number are Hispanic) and to births among these groups. With this continuing influx of citizens with different languages and diverse ethnic backgrounds, it is imperative to gather accurate demographic and cultural data about these groups in order to provide targeted arthritis awareness and management services.

The rapid "aging" of the U.S. population is a well documented demographic fact. According to the 2000 census, 12. I percent of Illinois' population is 65 years of age or older. In 2010, when the "baby boomers" begin to reach age 65, the proportion of persons in this age group will be 12.5 percent (U.S. Bureau of Census). Because the prevalence of arthritis is higher in this age group, additional burden will be placed on the established health care infrastructure to serve the needs of those persons.

#### SPECIAL POPULATIONS Uninsured/Under-insured

Another factor that may influence the increased cost to the public from arthritis is the number of persons who are uninsured or under-insured. Population estimates taken from the 2000 BRFSS showed that 11.4 percent of adults (age 18-64 years) statewide had no health insurance.

#### **Disabled/Unemployed**

In general, disabled persons are a particularly vulnerable group from the standpoint that they may be more likely to be unemployed because of their disabilities and, therefore, reliant on entitlement programs to both support them and to provide health care insurance. Statistics from the 1990 census support this point. Approximately 9 percent of Illinois' population (ages 16-64) in 1990 was disabled. This was defined as work-related disability, mobility limitations or self-care limitations. A person with arthritis could easily fit into any or all of these categories. The unemployment rate for this group was 13 percent, almost twice the statewide unemployment rate at the time. Fully onequarter of these persons also were living below the poverty level and only 62 percent were high school graduates (82 percent of Illinois residents reported being high school graduates in 1990). It takes little imagination to recognize the economic costs to state government when disabilities affect a large percentage of the population.

#### **Rural and Under-served Populations**

The BRFSS divides Illinois counties into three groups, based on demographic profiles and economic factors, for purposes of comparative assessment:

- the city of Chicago and suburban areas of Cook County;
- 2. urban counties; and
- 3. rural counties.

The BRFSS defines "rural counties" as those that are not part of the Chicago metro area and/or do not contain a large (population over 50,000) city within them. According to this, 83 Illinois counties are rural. The Illinois Project for Local Assessment of Needs (IPLAN), an innovative community health assessment and planning model designed to identify community health problems and to propose solutions through a comprehensive and on-going planning process, estimates that approximately 18 percent of the state's population lived in rural counties in 2000.

IDPH's Center for Rural Health defines a "rural county" as one that is not part of a metropolitan statistical area, as defined by the U.S. Bureau of the Census, or one that is part of a metropolitan statistical area but has a population of less than 60,000. According to this definition, 84 of Illinois' 102 counties are rural. Center staff work with local health care providers and interested community organizations to determine the availability of primary care providers in a county or service area (usually a portion of a county). If the area meets specific criteria, then it can be designated as a federal or state shortage or underserved area. There are various types of shortage designations:

 Federally designated health professional shortage area (HPSA). As of February 15, 2002, 93 Illinois counties were designated, in whole or part or by low-income population, by the U.S. Department of Health and Human Services as HPSAs. In addition, 55 facilities and one homeless population group were designated in Illinois. (See map, Appendix B.)

- Medically underserved area or population (MUA or MUP). As of February 15, 2002, there were 18 MUAs or MUPs in Illinois.
- Illinois designated primary care provider shortage area. As of February 15, 2002, 93 Illinois counties, in whole or in part or by low income population, were designated by the Illinois Department of Public Health as having a shortage of primary care providers. (See map, Appendix C.)
- Areas qualifying for Medicare certification under the Rural Health Clinic Act. As of February 15, 2002, all or part of 78 rural counties in Illinois qualify for Medicare certification under the Rural Health Clinic Act.

In these rural and under-served areas, lack of transportation and limited or non-existent health services are just two of the barriers these populations face. Lack of adequate access to patient education and preventive services, the hallmark of a public health approach to chronic disease control, could exacerbate the burden arthritis poses for rural and underserved populations.

#### **ILLINOIS DATA CHALLENGES**

The many burdens of arthritis and the needs of target populations must be understood to accurately gauge the impact of this disease on the people of Illinois. Because surveillance and epidemiology have long been recognized as cornerstones of a public health approach to chronic disease awareness and prevention, development of additional data systems to collect, analyze, interpret and disseminate information on arthritis in Illinois is a top priority. One way Illinois is currently addressing this issue is through the collection of county-specific BRFSS data, which should be available for each of Illinois' 102 counties by 2004.

Although BRFSS provides a useful tool to measure arthritis in Illinois, additional data sources are needed to provide a more thorough understanding of the burden

of arthritis in Illinois—the persons already impacted; those at risk for development of the disease; the extent and types of burdens faced by those directly or indirectly affected by arthritis; and interventions, services and educational resources available and needed.

Human and financial resources also are limited. Many successes have been realized thus far, even within these limitations; however, more must be achieved. IDPH is committed to supporting surveillance efforts and will hire an epidemiologist in 2002. Many members of the partnership and the work groups have been diligent in seeking additional program funding.

#### THE FUTURE

The Illinois Arthritis Partnership has identified the collection of statewide incidence, prevalence and disability data related to arthritis to be an important first task in developing a comprehensive arthritis surveillance system. Since 2000, Illinois has included arthritis and arthritis quality of life questions on its BRFSS. This data will provide estimates of the statewide prevalence of arthritis and the impact it has on quality of life. County-specific data, which will be collected from 2001-2004, will assist state and local public health agencies in more effectively targeting arthritis interventions and messages. In addition, these data will provide an important baseline in targeting resources and in evaluating progress in the provision of public health services to persons affected by arthritis.

## LESSENING THE BURDEN OF ARTHRITIS

#### PUBLIC HEALTH APPROACH TO ADDRESSING ARTHRITIS IN ILLINOIS

"Public health" can be defined as "activities that society undertakes to assure the conditions in which people can be healthy. This includes organized community efforts to prevent, identify and counter threats to the health of the public" (Turnock, 1997). The Illinois Arthritis Partnership decided a public health approach would be the most effective way to address arthritis in the state. Such an approach would be broad in scope, encompassing whole population groups in contrast to the classic medical approach, which addresses the individual patient. It would be multi-level, targeting individuals, families and communities and employing multiple strategies, such as community awareness and mobilization, health education and public policy changes, to improve community health. And it would recruit all those with a stake in improving the quality of life in persons affected by arthritis-the individual, his or her family and health provider, the health care system and community resources into the process.

The challenge for public health in addressing arthritis and other diseases and conditions is to identify and help to implement strategies for improving the health of target groups. One key component to the public health model for arthritis is the concept of prolonging health and preventing the disease. This concept has three levels: primary prevention, secondary prevention and tertiary prevention. Following is a description of each level.

**I. Primary prevention** is designed to prevent a disease or condition (arthritis, for example) from occurring. Adolescent tobacco control programs to reduce youth smoking initiation and physical activity programs to reduce the risk of heart disease are examples of primary prevention measures.

Five primary prevention strategies are considered effective for arthritis:

- <u>Weight control.</u> Maintaining an appropriate weight lowers a person's risk for knee osteoarthritis, a common form of the disease. Excessive body weight substantially increases stress on body joints.
- <u>Physical activity.</u> Regular participation in physical activity is known to help persons manage their weight as well as to provide other cardiovascular and quality of life benefits.

- <u>Occupational injury prevention</u>. An ergonomically sound work environment that avoids repetitive joint strain can prevent subsequent injury and the onset of arthritis.
- <u>Sports injury prevention.</u> Using recommended injury prevention strategies (e.g., warm-ups, strengthening exercises and appropriate equipment) helps to avoid joint injuries and damage to ligaments and cartilage, all of which can increase the risk of osteoarthritis.
- <u>Infectious disease control.</u> Certain protective strategies can prevent tick bites, which may cause Lyme disease and associated arthritis. Such strategies include using insect repellents, wearing long-sleeved shirts and pants when walking in the woods, and being educated on tick recognition and removal.

2. Secondary prevention attempts to identify a disease in its earliest stage so that prompt and appropriate management can be initiated. Successful secondary prevention reduces the impact of existing disease. Mammograms to detect early breast cancer are an example of a secondary prevention measure.

The following secondary prevention strategies are available but probably under-used:

- <u>Early diagnosis</u>. Early diagnosis of all types of arthritis is important. Many people with arthritis, particularly men and young people, never see a physician for the condition, especially if they are in generally good health, have few activity or work limitations due to their arthritis, have no health insurance or are overweight.
- <u>Self-care</u>. It is important that persons who have arthritis learn early in the course of the disease what they can do to minimize its impact and to maximize their functioning.
- <u>Physical activity</u>. Persons with arthritis need to learn how to exercise safely and need access to physical activity programs that have been designed specifically for persons with their needs.
- <u>Weight control.</u> Weight loss can improve functioning and reduce pain for many forms of arthritis.
- <u>Medical treatment.</u> Antibiotic treatment for early Lyme disease can prevent later stage complications, including arthritis.

## LESSENING THE BURDEN OF ARTHRITIS

**3. Tertiary prevention** focuses on reducing or minimizing the consequences of a disease once it has developed. Its goal is to eliminate, or at least delay, the onset of complications and disability due to the disease. Most medical interventions are included in this level. An example of tertiary prevention is strict control of blood glucose levels in a person with diabetes to prevent complications.

Tertiary prevention strategies for arthritis can reduce pain and disability, increase a person's confidence in his/her ability to manage arthritis related problems and improve quality of life.

 <u>Rehabilitation and self-management</u>. (self-management defined as "being willing to learn about treatment options and assume responsibility for using them in the daily care of arthritis").

Weight control is essential to decrease the load on already damaged joints. Physical activity and proper diet are important components of a disease management program.

**Physical activity** maintains joint health and also may reduce the risk of other adverse outcomes unrelated to arthritis, such as premature death, heart disease, diabetes, high blood pressure and colon cancer. Studies indicate that an exercise program can improve aerobic capacity and alleviate depression and anxiety among people with arthritis.

**Education** enables patients to become successful arthritis self-managers, balancing exercise, physical activity, relaxation, medication, pain management and problem solving.

- <u>Medical management.</u> Analgesics and non-steroidal anti-inflammatory drugs (NSAIDs) can offer pain relief. Disease-modifying anti-rheumatic drugs may protect cartilage. Drugs to lower uric acid levels can prevent attacks of gout.
- Joint replacement. Hip, knee or shoulder replacement surgery may benefit persons with advanced joint disease by relieving pain and improving function.

With a strong foundation in patient education, persons with arthritis can learn to design their own physical activity, relaxation and pain management programs and can learn methods for solving many of the problems that arise from the disease.

#### APPLYING THE PUBLIC HEALTH APPROACH: ESTABLISHING THE ARTHRITIS PARTNERSHIP AND WORK GROUPS

To carry out the activities of the initiative, IDPH first established the Illinois Arthritis Partnership and four work groups to address different aspects of the disease and its prevention and control. The four work groups are Surveillance and Data, Public Education, Professional Education/Health Care Systems, and Public Policy and Infrastructure.

The **Surveillance and Data Work Group** is focusing on the identification of existing and potential statewide data sources, planning for the development of a statewide surveillance system and providing technical data support to state and local users and to other work groups.

The **Public Education Work Group**'s focus is on identifying appropriate program target groups, resources and materials, developing awareness and education strategies and interventions, encouraging the use of appropriate health education models and supporting the initiative's efforts.

**Professional Education/Health Care Systems Work Group** is focusing on the identification of professional education target groups and on exploring intervention strategies derived from evidence-based strategies to increase educational opportunities for health care professionals and to improve health care system outcomes.

The **Public Policy and Infrastructure Work Group**'s focus is on securing legislative support for the initiative's state and local efforts and on exploring the need for advocacy efforts.

#### CORE FUNCTIONS OF THE ILLINOIS ARTHRITIS PARTNERSHIP

The Illinois Arthritis Partnership has identified a core set of functions needed for organizing programs and providing services to pursue the state's efforts to address this chronic disease. They include, but are not limited to the following:

1. Leadership for overall program coordination and implementation IDPH employs two full-time staff to oversee the current programa coordinator and a program specialist. Initiative funding has enabled the

## LESSENING THE BURDEN OF ARTHRITIS

program to secure services of an evaluator. Funding for staff, physical resources and IAI projects is provided by the CDC.

#### 2. <u>Accountability to ensure that programs are implemented</u> <u>with integrity and evaluated for effectiveness</u> The evaluator is involved in all aspects of the project

and is instrumental in the development of techniques and tools to assess effectiveness of efforts.

#### 3. <u>Surveillance and data collection to assess the burden of</u> <u>arthritis, arthritis-related disability, risk factors, and policy and</u> <u>program functions</u>

The initiative's Surveillance and Data Work Group, chaired by the program's epidemiologist, has developed an *Illinois Arthritis Data Report* and continuously seeks additional means of surveillance.

4. <u>Partnership (Advisory Committee) and Work Groups</u> The initiative has been aided by a dedicated and active partnership and four work groups since the first year of the grant (1999). These groups are consulted on all project and grant efforts.

#### 5. Health communications activities

The Illinois Arthritis Partnership and its work groups strive to assess the health communication and education needs of core target groups. Interventions, messages and delivery strategies are based on identified needs.

#### 6. Policy support for arthritis program activities

The Public Policy and Infrastructure Work Group has successfully secured state legislative support (as well as that of non-legislative policy makers), IDPH management support, and support from other state and local entities to address arthritis policy issues.

#### EXISTING PUBLIC HEALTH CAPACITY IN THE ILLINOIS ARTHRITIS INITIATIVE

The IAI is rich in capacity to provide statewide arthritis programming. Many committed partners have fostered "win-win" relationships, such as utilizing the IAI goals to achieve their agency goals and will continue to do so. (Appendix D, Partnership Affiliations.) Partnering with the two state Arthritis Foundation (AF) chapters has proven to be extremely beneficial to the overall program. Both state chapter and branch office staff have been instrumental in offering trainings; expanding self-management opportunities; sharing resources, knowledge and experiences; and educating others, including partnership members, about arthritis issues.

Other partnership and work group members represent various disciplines and organizations: public health services, local health departments, the aging network, rural health advocates, minority group agencies, academia and the business/private sector. These dedicated professionals lead many of the IAI efforts by sharing knowledge and offering resources to address education, treatment, access, surveillance and policy issues. IDPH program staff continuously assess the need for additional partners and resources, and actively seek out new members as necessary. The partnership and work groups also explore methods to increase fiscal resources.

IDPH is committed to enhancing capacity through the addition of human resources. In 2002, an epidemiologist will be hired to oversee the development and maintenance of the comprehensive arthritis surveillance system. Also, IDPH continues to utilize the services of a program evaluator to assess program needs and progress. Finally, the Department provides funding to several community-based agencies to conduct arthritis awareness, prevention and self-management activities.

Although gaps in programming do exist, it is hoped that, by 2005, a vast array of services and resources will be available to adequately reduce the burden of arthritis in Illinois.

#### THE PLANNING PROCESS

Priorities, objectives and activities for addressing arthritis in Illinois were developed through the collaborative efforts of the Illinois Arthritis Partnership and its work groups. A framework has been created for a statewide public health approach to comprehensive arthritis prevention, management and control that encompasses the CDC, NAAP and HP 2010 objectives for reducing the burden of this disease.

#### ILLINOIS ARTHRITIS ACTION PLAN IMPLEMENTATION GUIDE

The Illinois Arthritis Action Plan Implementation Guide has been developed to coincide with each objective and its respective strategies. The following are cited for each strategy: action, responsible person, channel/venue, target population, measurable indicator, anticipated resources and due date.

The Illinois Arthritis Action Plan will be disseminated to state agencies, local Arthritis Foundation branch offices, local health departments, legislators, policy makers, partners, work group members, and a vast array of other agencies, organizations and institutions.

#### ILLINOIS' ARTHRITIS OBJECTIVES AND STRATEGIES

Following are the objectives, strategies (see separate document, *Illinois Arthritis Action Plan Implementation Guide* for actions corresponding to these strategies and actions) identified by each of the four work groups.

#### SURVEILLANCE AND DATA EFFORTS

**Rationale:** Surveillance and epidemiology provide the foundation for accurate, timely and reliable data related to arthritis. These data will help to identify resources and gaps in service and will further the development and dissemination of information. Data can provide an important impetus to develop appropriate policies to address the burden of arthritis in Illinois.

#### **OBJECTIVE: By 2005, implement a comprehensive** Illinois arthritis surveillance system.

**Strategy I.** Continue efforts begun in 2000 to regularly assess, prioritize and make provisions for the data needs of the partnership and work groups for their projects and for the initiative's special projects.

**Strategy 2.** Beginning in 2001, develop and periodically update a comprehensive surveillance and data work plan that continually assesses and evaluates existing data sources and methods by which new data sources can be added to fill identified gaps.

**Strategy 3.** Beginning in 2001, identify HP 2010 arthritisrelated objectives and develop a plan to collect data that will enable the IAI to achieve those objectives.

**Strategy 4.** Beginning in 2001, utilize available county-specific arthritis-related BRFSS data.

**Strategy 5.** Beginning in 2001, identify disparities in arthritis prevalence in different populations, specifically in the project's core target groups.

**Strategy 6.** Beginning in 2001, periodically monitor changes in the frequency of arthritis and its impact on disability and quality of life.

**Strategy 7**. In 2002, develop a baseline Illinois arthritis data report containing current data on the burden of arthritis in Illinois.

**Strategy 8.** Throughout the project, maintain a Surveillance and Data Work Group.

**Strategy 9.** By 2005, evaluate the comprehensive Illinois arthritis surveillance system.

#### **PUBLIC EDUCATION EFFORTS**

**Rationale:** Raising awareness of the burden of arthritis in Illinois and disseminating information related to effective strategies for arthritis diagnosis, management, treatment and prevention are important IAI goals. Public education efforts focus on increasing arthritis self-management opportunities, the number of persons with arthritis who attend self-management classes and awareness of Arthritis Foundation services; identifying key target audiences; and tailoring and disseminating appropriate health messages and programs.

**OBJECTIVE:** By 2005, improve access to education opportunities derived from evidence-based strategies for the public and for persons affected by arthritis.

**Strategy I.** Continue efforts begun in 2000 to identify core target groups for arthritis public awareness and education efforts.

**Strategy 2.** Continue efforts begun in 2000 to assess and develop a report detailing the educational needs of affected persons in core target groups and others as identified/needed.

**Strategy 3.** Continue efforts begun in 2000 to develop a mechanism to make arthritis resources (including access to caregivers and materials) available electronically.

**Strategy 4.** Continue efforts begun in 2000 to develop a model arthritis work site project and share findings with other businesses throughout the state.

**Strategy 5.** Beginning in 2001, seek out or develop educational resources and interventions derived from evidence-based strategies that respond to identified needs of core target groups.

**Strategy 6.** Beginning in 2001, encourage local and state government agencies to incorporate ongoing arthritis awareness and education into their existing chronic disease prevention, health promotion and public education efforts.

**Strategy 7.** Beginning in 2001, improve the ability of persons with arthritis to make informed decisions about the use of complementary and alternative medicine.

**Strategy 8.** Beginning in 2001, develop and establish a plan for a school-based program designed to educate families of children with juvenile rheumatoid arthritis about available treatment and self-management programs.

**Strategy 9.** Beginning in 2002, develop and implement an arthritis communication campaign to promote early diagnosis, treatment and self-management of arthritis among core target groups and others as identified/needed.

**Strategy 10.** In each project year, increase the number of, and expand access to, evidence-based self-management and other community-based interventions for persons with arthritis.

**Strategy II.** Throughout the project, maintain a Public Education Work Group.

**Strategy 12.** By 2005, evaluate public education strategies and actions.

#### PROFESSIONAL EDUCATION/ HEALTH CARE SYSTEMS EFFORTS

**Rationale:** Professional education activities will focus on primary care providers, including physicians, nurse practitioners and physician assistants. As efforts progress, education may eventually be offered to other health professionals (e.g., public health professionals, allied health professionals, health educators). Efforts will benefit those health professionals with an interest in learning more about diagnosis, management, treatment and prevention of arthritis. The NAAP guidelines will be used to assess the educational needs of health professionals.

### **OBJECTIVE:** By 2005, improve arthritis knowledge, attitudes, and referral practices of primary health care professionals.

**Strategy I.** Continue efforts begun in 2000 to identify core target groups for arthritis professional education efforts.

**Strategy 2.** Continue efforts begun in 2000 to develop a plan to create arthritis partnerships between state and local health agencies and primary care professional organizations.

**Strategy 3.** Continue efforts begun in 2001 to create arthritis partnerships between state and local health agencies, educational institutions and organizations that have expertise in providing continuing education for health care professionals.

**Strategy 4.** Continue efforts begun in 2001 to assess and develop a report of the arthritis professional education needs of providers.

**Strategy 5.** Beginning in 2001, develop an interactive arthritis professional education program.

**Strategy 6.** Beginning in 2002, implement interactive professional education programs derived from evidence-based strategies for members of core target groups.

**Strategy 7.** Beginning in 2004, expand professional education efforts based on evaluation of previous professional education interventions.

**Strategy 8**. Throughout the project, maintain a Professional Education Work Group.

**Strategy 9.** By 2005, evaluate the knowledge, attitudes and referral practices of health care professionals who serve core target groups.

#### PUBLIC POLICY AND INFRASTRUCTURE EFFORTS

**Rationale:** A statewide plan that emphasizes the importance of policy development and implementation could greatly enhance efforts to reduce the burden of arthritis in Illinois. The partnership will utilize the strong public health infrastructure that already exists in Illinois to effectively support arthritis prevention and intervention activities.

### **OBJECTIVE:** By 2005, increase appropriate resources and funding for statewide and local arthritis and arthritis disability prevention programs.

**Strategy I.** Continue efforts begun in 2000 to create and sustain an increasingly effective coalition to promote aggressive state arthritis and arthritis disability policies, including securing state funding for comprehensive arthritis activities.

**Strategy 2.** Continue efforts begun in 2000 to increase the capacity (including human resources) of the state and local public health infrastructure to conduct surveillance/data collection, and public and professional education, and to provide leadership in policy development that would facilitate arthritis and arthritis disability prevention activities.

**Strategy 3.** Continue efforts begun in 2000 to identify strategies for increasing Illinois decision makers' awareness of arthritis and arthritis disability as public health problems.

**Strategy 4.** Beginning in 2001, assist other IAI work groups to address their prioritized legislative and policy issues.

**Strategy 5.** Throughout the project, maintain a Public Policy and Infrastructure Work Group.

**Strategy 6.** By 2005, evaluate the public policy strategies and actions.

PROGRAM MANAGEMENT EFFORTS
<b>Rationale:</b> The effective and organized management of the initiative is vital to the success of a comprehensive arthritis program that will effectively reduce the burden of arthritis in Illinois.
<b>OBJECTIVE:</b> Throughout the life of the project, enhance and maintain overall activities to improve program components and operations.
<b>Strategy I.</b> Throughout the life of the project, maintain existing partners and work group members, and recruit others to serve on the Illinois Arthritis Partnership.
<b>Strategy 2.</b> Beginning in 2000, secure the services of a project epidemiologist to provide surveillance and data support to the initiative and its components and to oversee the development of a comprehensive arthritis surveillance system.
<b>Strategy 3.</b> Beginning in 2000, secure the services of a project evaluator to assess processes and effectiveness of overall program operation and individual projects and work group efforts.
<b>Strategy 4.</b> Beginning in 2001, develop and periodically update the <i>Illinois Arthritis Action Plan</i> , citing objectives, strategies and proposed actions.
<b>Strategy 5.</b> Throughout the life of the project, maintain and foster the relationship with the Greater Chicago and Greater Illinois Arthritis Foundations and their branch offices to assure local outreach of AF services and information.
<b>Strategy 6.</b> Throughout the life of the project, utilize <i>Healthy People 2010</i> and <i>National Arthritis Action Plan</i> objectives as a guide for state arthritis programming.
<b>Strategy 7.</b> Throughout the life of the project, maintain communication with other states involved with arthritis efforts to increase knowledge and enhance Illinois' initiative.

# **CONCLUSION**

his plan documents the profound impact of arthritis on Illinois' citizens now and in the future. Through the dedicated efforts of its many members, the Illinois Arthritis Partnership identified a comprehensive set of objectives, strategies and actions that provide a framework for a statewide public health approach to arthritis prevention and control.

Making this approach a reality will require continuing collaboration and commitment. By joining forces, agencies and organizations can achieve the goal of arthritis prevention and control. There are important roles for all individuals and groups in supporting the objectives described in this plan. The partnership challenges everyone to identify ways to contribute to this important effort, and to help transform the vision of this plan into reality.

# HEALTHY PEOPLE 2010

#### THE CENTRAL GOALS OF HEALTHY PEOPLE 2010

### Healthy People 2010 is designed to achieve two overarching goals:

- · Increase quality and years of healthy life
- Eliminate health disparities

#### **HP2010 Definition of Objectives**

There are two types of objectives—measurable and developmental.

Measurable objectives. Measurable objectives provide direction for action. For measurable objectives, the current status is expressed with a national baseline. The baseline represents the starting point for moving the Nation toward the desired end. The baselines use valid and reliable data derived from currently established, nationally representative data systems. Some of these systems build on, or are comparable with, State and local data systems. However, State data are not a prerequisite to developing an objective. Non-national data may be used where national data are not available. These situations are noted in the baseline data for the objective. The data source for each measurable objective is identified. Baseline data provide the point from which a 2010 target is set. Where possible, objectives are measured with nationally representative data systems. (See Tracking Healthy People 2010, produced by National Center for Health Statistics, for an operational definition for each measurable objective.)

**Developmental objectives.** Developmental objectives provide a vision for a desired outcome or health status. Current national surveillance systems do not provide data on these subjects. The purpose of developmental objectives is to identify areas of emerging importance and to drive the development of data systems to measure them. Most developmental objectives have a potential data source with reasonable expectation of data points by the year 2004 to facilitate setting year 2010 targets in the mid-decade review. Developmental objectives with no baseline at the midcourse will be dropped.

#### **Arthritis-Related Objectives**

- 2-1 (Developmental) Increase the mean number of days without severe pain among adults who have chronic joint symptoms.
- 2-2 Reduce the proportion of all adults with chronic joint symptoms who experience a limitation in activity due to arthritis.

- 2-3 Reduce the proportion of all adults with chronic joint symptoms who have difficulty in performing two or more personal care activities, thereby preserving independence.
- 2-4 (Developmental) Increase the proportion of adults aged 18 and older with arthritis who seek help in coping if they experience personal and emotional problems.
- 2-5 Increase the employment rate among adults with arthritis in the working-age population.
- 2-6 (Developmental) Eliminate racial disparities in the rate of total knee replacements.
- 2-7 (Developmental) Increase the proportion of adults who have seen a health care provider for their chronic joint symptoms.
- 2-8 (Developmental) Increase the proportion of persons with arthritis who have had effective, evidence-based arthritis education as an integral part of management of their condition.

#### Second tier objectives

(too little data available to be a formal objective)

- Increase the proportion of persons with systemic rheumatic disease who receive an early specific diagnosis and appropriate management plan.
- Increase the proportion of hospitals, managed care organizations, and large group practices that provide effective, evidence-based arthritis education for patients to use as an integral part of the management of their condition.
- Increase the proportion of persons at risk for or who have arthritis who receive counseling from their health care provider about weight control and physical activity to prevent arthritis-related disabilities.

#### Nutrition and Overweight (Chapter 19)

- 19-1 Increase the proportion of adults who are at a healthy weight.
- 19-2 Reduce the proportion of adults who are obese.

#### Physical Activity and Fitness (Chapter 22)

- 22-1 Reduce the proportion of adults who engage in no leisure-time physical activity.
- 22-2 Increase the proportion of adults who are obese.
- 22-3 Increase the proportion of adults who engage in vigorous physical activity that promotes the development and maintenance of cardiorespiratory fitness three or more times per week for 20 minutes or more per occasion.

### **FEDERALLY DESIGNATED** HEALTH PROFESSIONAL SHORTAGE AREAS IN ILLINOIS APPENDIX B





# **ARTHRITIS PARTNERSHIP AFFILIATIONS**

**APPENDIX D** 

**Advocate Health Care Arthritis Foundation Aventis Pharmaceuticals** Chicago On Department on Aging **Chicago Medical School Illinois Academy of Family Physicians Illinois Area Health Education Centers Illinois Department of Public Health** Division of Chronic Disease Prevention and Control Division of Governmental Affairs Center for Minority Health Services Center for Rural Health Office of Women's Health **Illinois Department on Aging Illinois Department of Human Services Illinois Health Care Association Illinois Nurses Association Illinois Pharmacists Association Illinois Primary Health Care Association** LaHarpe Davier Rural Health Center **Local Health Departments** Bureau County Health Department Edgar County Health Department Ford-Iroquois County Health Department Greene County Health Department Jersey County Health Department Knox County Health Department Lake County Health Department Livingston County Health Department Madison County Health Department Marion County Health Department McDonough County Health Department Mercer County Health Department Montgomery County Health Department Pike County Health Department Sangamon County Health Department Tazwell County Health Department Will County Health Department

Merck and Company Inc. MidState Rheumatology Associates Northwestern University Medical School Northwestern University, Office of Clinical **Research and Training** Office of the Secretary of State, Senior and **Community Services Older Women's League Illinois Pharmacia Corporation** Pfizer Inc. Rush-Presbyterian-St. Luke's Medical Center **Springfield Clinic** SwedishAmerican Health System University of Illinois at Chicago College of Medicine College of Medicine, Regional Program in Peoria College of Medicine, Regional Program in Rockford Health Policy and Research Centers School of Public Health Center for Research on Health and Aging University of Illinois Extension Visiting Nurses Association of Central Illinois

### GLOSSARY OFTERMS APPENDIXE

**ARTHRITIS.** In simple terms, arthritis means joint inflammation. It encompasses more than 120 rheumatic diseases and conditions affecting joints, the surrounding tissues and other connective tissues. It may cause pain, stiffness and swelling not just in joints but other supporting structures of the body such as muscles, tendons, ligaments and bones. Some rheumatic diseases are also autoimmune disorders and affect other parts of the body, including internal organs.

#### **BEHAVIORAL RISK FACTOR SURVEILLANCE**

**SURVEY.** The Behavioral Risk Factor Surveillance Survey (BRFSS) is an ongoing, state-based, random-digitdialed telephone survey that annually collects self-report health information from a representative sample of the civilian noninstitutionalized U.S. population 18 years of age or older. All 50 states and the District of Columbia report BRFSS data to the CDC.

#### COMPLEMENTARY/ALTERNATIVE MEDICINE.

Complementary/alternative medicine (CAM) covers a broad range of healing philosophies, approaches and therapies that mainstream, conventional medicine does not commonly accept. Examples of CAM practices include acupuncture, herbs, homeopathy, therapeutic massage and traditional oriental medicine to promote well-being or to treat health conditions.

**CORE STATE.** In 1999, CDC funded eight "core states" and 30 "establishment states." The core states were funded for four years, and the establishment states were funded for three years. The eight core states are Alabama, California, Florida, Georgia, Illinois, Minnesota, Missouri and Utah.

**CORE TARGET GROUPS.** Initial projects will focus on people affected by arthritis including underserved, uninsured and minority groups in Illinois. In addition, persons with osteoarthritis, rheumatoid arthritis, fibromyalgia, lupus, juvenile rheumatoid arthritis and gout will be targeted.

**DISABILITY.** In medical terms, disability means incapacity, that is, a lack of the ability to function normally. For purposes of entitlement, disability means the inability to engage in any substantial gainful activity due to a medically determinable physical or mental impairment for a continuous period of at least 12 months.

**EPIDEMIOLOGY.** Epidemiology may be defined as the study of the distribution and determinants of diseases and injuries in human populations. In other words, epidemiology is concerned with the frequencies and types of illnesses and injuries in groups of people and with the factors that influence the distribution.

**ERGONOMICS.** The word "ergonomics" comes from the Greek words "ergon" meaning work and "nomos" meaning laws. Today, however, the word is used to describe the science of "designing the job to fit the worker, not forcing the worker to fit the job." Ergonomics covers many aspects of a job: from the physical stresses placed on joints, muscles, nerves, tendons, bones, etc., to environmental factors that can affect hearing, vision, and general comfort and health.

**ESTABLISHMENT STATES.** Thirty states funded by CDC for three years to begin building capacity for arthritis awareness.

**EVIDENCE-BASED.** Evidence-based recommendations involve an evaluation of published information on a given topic (e.g., the association between exercise and osteoarthritis) and a determination of the most appropriate conclusions and recommendations for treatment strategies based on this information.

#### HEALTH PROFESSIONAL SHORTAGE AREA

(HPSA). HPSA designations may be based on geographic area, population group or facility. In addition, health care services in contiguous areas must be over-utilized, excessively distant or inaccessible to the population within the service area being considered for HPSA designation.

**HEALTHY PEOPLE 2010 (HP2010).** HP2010 is a comprehensive national health agenda designed to improve the health of all persons in the country by promoting health and by preventing illness, disability and premature death.

#### ILLINOIS PHYSICIAN SHORTAGE AREAS.

These areas, identified by the Illinois Department of Public Health, are those with a high population-toprimary care physician ratio.

#### MEDICALLY UNDERSERVED AREA (MUA).

This geographic designation made by the U.S. Department of Health and Human Services defines a service area composed of either whole counties, townships, census tracts or groups of contiguous census tracts. Weighted values are applied to four data elements to develop an overall score or "index of medical underservice" (IMU): service area population; percentage of the population below poverty and percentage over the age of 65; infant mortality rate; and current number of full-time equivalent primary care physicians serving the area and the computed ratio of primary care physicians per thousand population.

#### MEDICALLY UNDERSERVED POPULATION

(MUP). A population group residing in an area that does not meet the MUA criteria may be considered for MUP designation if unusual local conditions create barriers

### GLOSSARY o f t e r m s

to access to personal health services and the chief executive officer and/or local officials of the state recommend such designation. Requests for designation as a MUP must meet the MUA criteria mentioned above, including the computed index of medical underservice score. In addition, unusual location conditions, access barriers and health care availability must be described.

**MODIFIABLE RISK FACTORS.** These are risk factors that an individual can control to some extent. Examples of modifiable risk factors include the following:

- 1. Obesity—Maintaining an appropriate weight or reducing weight to a recommended level lowers a person's risk for certain common forms of arthritis.
- 2. Joint injuries—Injury prevention strategies, such as warm-ups, strengthening exercises and using appropriate equipment, help to avoid joint injuries and damage to ligaments and cartilage.
- 3. Infections—Certain protective strategies (e.g., using insect repellents, wearing long-sleeved shirts and pants when walking in the woods, and being educated on tick recognition and removal) can prevent the tick bites that cause Lyme disease and associated arthritis.
- 4. Certain occupations—Certain occupations, such as construction, farming, heavy industry and occupations with repetitive knee-bending, can increase a person's risk for certain types of arthritis.
- 5. Late diagnosis—Early diagnosis of all types of arthritis is important. Early and accurate diagnosis and treatment can often mean less pain and joint damage. In the case of rheumatoid arthritis, for example, many researchers believe that there is a two-year window of time at the beginning of the disease during which aggressive drug therapy can shift the course of the disease away from irreversibility.

#### NATIONAL ARTHRITIS ACTION PLAN

(NAAP). The National Arthritis Action Plan is a collaborative effort of the Arthritis Foundation, the Association of State and Territorial Health Officials and the U.S. Centers for Disease Control and Prevention working with 90 other organizations. The plan strives to increase public awareness of the impact of arthritis and to educate those reviewing the plan about what can be done to prevent or delay the onset of arthritis. It also identifies effective, available interventions to reduce disability and to improve quality of life for persons with arthritis. This focus successfully integrates the perspective, values and resources of the public health and arthritis communities in a mutual effort to reduce the national burden of the disease.

**NON-MODIFIABLE RISK FACTORS.** There are some risk factors for arthritis that cannot be controlled by an individual. These include the following: Gender–Women appear to be disproportionately affected by arthritis. Those 15 years of age and older account for 60 percent of arthritis cases.

Age—Older age is also associated with increased risk of arthritis. Nearly half of all persons 65 years of age and older are affected by arthritis. Although age is a risk factor, research shows that arthritis is not an inevitable part of aging.

Genetic predisposition—Certain genes are known to be associated with a higher risk of some types of arthritis. For example, genetics has a role in the development of osteoarthritis and rheumatoid arthritis.

**PARTNERSHIP.** The partnership acts as an advisory committee for the Illinois Arthritis Initiative. It consists of approximately 75 members representing more than 55 organizations statewide (see Appendix D). Membership is open to anyone interested in arthritis issues. The group meets approximately twice a year.

**RURAL.** The BRFSS defines "rural counties" as those that are not part of the Chicago metro area and/or do not contain a large (population over 50,000) city within them. According to this, 83 Illinois counties are rural. IDPH's Center for Rural Health defines a "rural county" as one that is not part of a metropolitan statistical area, as defined by the U.S. Bureau of the Census, or one that is part of a metropolitan statistical area but has a population of less than 60,000. According to this definition, 84 of Illinois' 102 counties are rural.

**SELF-MANAGEMENT.** Self-management is the willingness to learn about treatments to control a disease and to assume responsibility for using them in daily care. This includes, but is not limited to, keeping informed about personal health status, taking an active part in planning the treatment program, trying different treatments (under the guidance of a health care team) to develop an optimal treatment program, informing the health care team about problems and changes in one's daily program, and setting goals and working toward them.

**SURVEILLANCE.** Surveillance is the systematic collection, analysis, interpretation and dissemination of data pertaining to the occurrence of specific diseases.

**WORK GROUPS.** The Illinois Arthritis Initiative consists of four work groups whose members serve as advisers in specific areas. The work groups are Surveillance and Data, Public Education, Professional Education, and Public Policy and Infrastructure. Each work group meets approximately six times per year.

## **ACRONYM LIST**

**APPENDIX F** 

AF	Arthritis Foundation	
BRFSS	Behavioral Risk Factor Surveillance Survey	
CDC	U.S. Centers for Disease Control and Prevention	
HP2010	Healthy People 2010	
HPSA	Health professional shortage area	
IAI	Illinois Arthritis Initiative	
IDPH	Illinois Department of Public Health	
IPLAN	Illinois Project for Local Needs Assessment	
MUA	Medically underserved area	
MUP	Medically underserved population	
NAAP	National Arthritis Action Plan	
NSAIDs	Non-steroidal anti-inflammatory drugs	
SLE	Systemic lupus erythematosus	

## BIBLIOGRAPHY

#### APPENDIX G

Anderson, Jennifer J.; Wells, George; Verhoeven, Arco C. "Factors Predicting Response to Treatment in Rheumatoid Arthritis: The Importance of Disease and Duration." *Arthritis and Rheumatism* 43 (2000): 22.

Arthritis Foundation. "Arthritis Types and Prevalence." www.arthritis.org

Arthritis Foundation, Association of State and Territorial Health Officials, and Centers for Disease Control and Prevention. *National Arthritis Action Plan.* (1999).

Cerhan, J.; Wallace, R.; el-Khoury, G.; Moore, T.; Long, C. "Decreased Survival with Increasing Prevalence of Full-body, Radiographically Defined Osteoarthritis in Women." *American Journal of Epidemiology* 141 (1995): 225-234.

Chehata J.; Hassell, A.; Clarke, S.; Mattey, D.; Jones, M.; Jones, P.; Dawes, P. "Mortality in Rheumatoid Arthritis: Relationship to Single and Composite Measures of Disease Activity." *Rheumatology*, 40 (2001): 447-452.

Felson, D.T.; Hannan, M.T.; Naimark, A., et al. "Occupational Physical Demands, Knee Bending, and Knee Osteoarthritis: Results from the Framingham Study." *Journal of Rheumatology* 18 (1991): 1587-92.

Felson, D.T.; Zhang, Y.; Anthony, J.M.; et al. "Weight Loss Reduces the Risk of Symptomatic Knee Osteoarthritis in Women." *Annals of Internal Medicine* 116 (1992): 535-9.

Felson, D.T. and Zhang, Y. "An Update on the Epidemiology of Knee and Hip Osteoarthritis with a View to Prevention." *Arthritis and Rheumatism* 41 (1998): 1343-55.

French, A.; Mason, T.; Nelson, A.; O'Fallon, W.; Gabriel, S. "Increased Mortality in Adults with a History of Juvenile Rheumatoid Arthritis: A Population-based Study." *Arthritis and Rheumatism* 44 (2001): 523-527.

Gortmaker, S.L. and Sappenfield, W. "Chronic Childhood Disorders: Prevalence and Impact." *Pediatric Clinics or North America* 31 (1984): 3.

Hutchinson, D.; Shepstone, L.; Moots, R.; Lear, J.T.; Lynch, M.P. "Heavy Cigarette Smoking is Strongly Associated with Rheumatoid Arthritis (RA), Particularly in Patients Without a Family History of RA." *Annals of Rheumatologic Disease* 60 (March, 2001): 223-7.

77 Illinois Administrative Code, Part 590, Section 590.40

Illinois Department of Public Health. Illinois Behavioral Risk Factor Surveillance System. 1999, 2000.

Illinois Project for Local Assessment of Needs

Lorig, Kate; Manzonson, P.D.; and Holman, H.R. "Evidence Suggesting that Health Education for Self-Management in Patients with Chronic Arthritis has Sustained Health Benefits While Reducing Health Care Costs." Arthritis and Rheumatism 36 (1993): 439-46.

Mausner, Judith and Kramer, Shira. Mausner and Bahn Epidemiology–An Introductory Text. Philadelphia: W.B. Saunders Company, (1985).

Minor, M.A.; Allegrante, J.P. "Exercise in the Management of Osteoarthritis of the Hip and Knee." In: Hamerman, D, ed. Osteoarthritis: Public Health Implications for an Aging Population. Baltimore, MD: Johns Hopkins University Press, (1997).

Minor, M.A.; Hewett, J.E.; Webel, R.; et al. "Efficacy of Physical Conditioning Exercise in Rheumatoid Arthritis and Osteoarthritis." *Arthritis and Rheumatism* 32 (1989): 1396-1405.

Minor, M.A.; Hewett, J.E.; "Physical Fitness and Work Capacity in Women with Rheumatoid Arthritis." *Arthritis Care Research* 8 (1995): 146-54.

Minor, M.A.; Lane, N.E. "Recreational Exercise in Arthritis." *Rheumatic Diseases Clinics of North America* 22 (1996): 563-77.

National Institutes of Health, National Institute of Arthritis and Musculoskeletal and Skin Diseases. "Handout on Health: Systemic Lupus Erythematosis." NIH Publication Number 97-4878. (February, 1999).

## BIBLIOGRAPHY

National Institutes of Health, National Institute of Arthritis and Musculoskeletal and Skin Diseases. "Handout on Health: Osteoarthritis." NIH Publication Number 99-4617. (June, 1999).

National Institutes of Health, National Institute of Arthritis and Musculoskeletal and Skin Diseases. "Questions and Answers About Arthritis and Rheumatoid Diseases." Publication Number AR-27QA. (February, 1999).

National Institutes of Health, National Institute of Arthritis and Musculoskeletal and Skin Diseases. "Questions and Answers About Fibromyalgia." Publication Number AR-91QA. (December, 1999).

National Institutes of Health, National Institute of Arthritis and Musculoskeletal and Skin Diseases. "Questions and Answers About Gout." Publication Number AR-99QA. (December, 1998).

National Institutes of Health, National Institute of Arthritis and Musculoskeletal and Skin Diseases. "Questions and Answers About Juvenile Rheumatoid Arthritis." Publication Number AR-112QA. (May, 1998).

Rahman, P.; Gladman, D.; Urowitx, M.; Hallett, D.; Tam, L. "Early Damage as Measured by the SLICC/ACR Damage Index is a Predictor of Mortality in Systemic Lupus Erythematosus." *Lupus*. 10 (2001): 93-96.

Rao, J.K.; Callahan, L.F.; Helmick, C.G. "Characteristics of Persons with Self-Reported Arthritis and Other Rheumatic Conditions Who Do Not See a Doctor." *Journal of Rheumatology* 24 (1997): 169-73.

Roubenoff, R.; Klag, M.J.; Mead, L.A.; et al. "Incidence and Risk Factors for Gout in White Men." *Journal of the American Medical Association* 266 (1991): 3004-7.

Schoen, R.T. "Identification of Lyme Disease." *Rheumatic Diseases Clinics of North America* 20 (1994): 361-9.

Steere, A.C. "Lyme Disease." New England Journal of Medicine 321 (1990): 586-96.

Straus, S.E. "Evidence-Based Medicine: A Commentary on Common Criticisms." *Canadian Medical Association Journal*, 163 (2000): 837-841.

Taber's Cyclopedic Medical Dictionary. 13<sup>th</sup> Edition. (1977).

Turnock, Bernard J. Public Health: What It Is and How It Works. Gaithersburg, MD, Aspen Publishers, Inc., (1997).

U.S. Census Bureau. "Redistricting Data." *Census 2000.* www.census.gov

U.S. Census Bureau. Census 1999. www.census.gov

U.S. Centers for Disease Control and Prevention. "Arthritis Prevalence and Activity Limitations – United States." *Morbidity and Mortality Weekly Report* 43. (1994): 433-8.

U.S. Department of Health and Human Services. "Targeting Arthritis: The Nation's Leading Cause of Disability." *At-A-Glance*. (2000).

U.S. Department of Health and Human Services. *Federal Register*, vol. 45, no 223. Washington, D.C.:GPO, (November 17, 1980).

U.S. Department of Health and Human Services. *Federal Register*. Washington, D.C.:GPO, (November 5, 1982).

U.S. Department of Health and Human Services. *Healthy People 2010*. Washington, D.C.:GPO, (2000).

U.S. Department of Health and Human Services. *Physical Activity and Health: A Report of the Surgeon General.* Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, (1996).

U.S. Department of Health and Human Services. "Prevalence and Impact of Chronic Joint Syndrome–Seven States, 1996." *Morbidity and Mortality Weekly Report*, 47 (1998): 345-351.

Wolfe, F.; Mitchell, D.; Sibley, J.; Fries, J.; Bloch, D.; Williams, C.; Spitz, P.; Haga, M.; Kleinheksel, S.; Cathey, M. "The Mortality of Rheumatoid Arthritis." *Arthritis and Rheumatism.* 37 (1994): 481-494.

