



2006-2009

Illinois Arthritis Action Plan

July 2006



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2006-2009 ILLINOIS ARTHRITIS ACTION PLAN

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Rod R. Blagojevich, Governor
Eric E. Whitaker, M.D., M.P.H., Director

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July 2006

Dear Colleague:

In 2002, approximately 43 million Americans (or about one in five) reported doctor-diagnosed arthritis and another 23 million people reported possible arthritis (chronic joint symptoms but had not been told by a doctor that they had arthritis), making it one of the most prevalent diseases in the United States. As the baby boom generation ages, the number of persons aged 65 and older who report doctor-diagnosed arthritis is projected to more than double from 15.7 million in 2002 to 33.3 million in 2030.

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 \$86.2 billion in total costs (\$51.1 billion in direct costs and \$35.1 billion in indirect costs). Arthritis affects the quality of life of the person who experiences this often disabling, 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 2.1 million, or 22.7 percent, of Illinois citizens live with some form of arthritis. The *Illinois Arthritis Action Plan: 2006-2009* provides a framework for addressing the burden of arthritis in Illinois. The plan emphasizes—

- Expanding the reach of evidence-based arthritis self-management interventions;
- Maintaining and enhancing an existing scientific database on the prevalence and impact of arthritis and related disability; and
- Maintaining the existing Illinois Arthritis Partnership.

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: 2006-2009* 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.

Sincerely,

A handwritten signature in black ink that reads "Eric E. Whitaker M.D." with a stylized flourish at the end.

Eric E. Whitaker, M.D., M.P.H.
Director

Arthritis Action Plan: 2006-2009

Executive Summary

Arthritis includes more than 100 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 approximately 16 million of adults in America¹, thereby having a significant effect on quality of life, not only for the person with the disease, but also for family members and caregivers. This plan is an update to the “*Illinois Arthritis Action Plan: 2000-2005*”

The Facts

- In 2002, approximately 2.1 million, or 22.7 percent, of Illinois adults reported doctor-diagnosed arthritis, and another 9.1 percent (more than 850,000 of Illinois adults) reported having possible arthritis but had not been diagnosed by a healthcare provider.²
- More than two-fifths (40.9 percent) of all persons reporting doctor-diagnosed arthritis stated that their activities were limited because of their joint symptoms.²

The Challenge

Illinois’ diversity creates unique challenges for addressing the burden of arthritis. More than 22.7 percent of the state’s population resides in the city of Chicago;³ 84 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 the 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 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 underinsured, and the underserved.

Following are the plan's five major focus areas and supporting objectives to be achieved between years 2006 through 2009:

- **Surveillance and Data**
By 2009, maintain and expand an existing database on the prevalence and impact of arthritis and related disability.
- **Public Education**
By 2009, increase evidence-based arthritis self-management provisions, awareness and education opportunities for persons with arthritis and their caregivers.
- **Professional Development and Health Care Systems**
By 2009, improve arthritis knowledge, attitudes and referral practices of local health providers and Arthritis Foundation self-management leaders.
- **Public Policy and Infrastructure**
By 2009, increase appropriate resources and funding for statewide and local arthritis and arthritis disability prevention programs.
- **Program Management**
Throughout the life of the project, enhance and maintain overall management activities to improve program components and operations.

The Mission

The mission of the Illinois Arthritis Initiative (IAI) is improving the quality of life for Illinoisans affected by arthritis. The state of Illinois, consistent with objectives identified in the *National Arthritis Action Plan*, is striving to strengthen statewide capacity and resources to surveillance and data activities, offer effective interventions and create and support policy to achieve the following:

- expand the reach of evidence-based self-management interventions;
- promote early diagnosis, treatment and appropriate management of arthritis to ensure the highest quality of life for people with the disease;
- prevent arthritis, when possible, through recognition and modification of risk factors;
- increase awareness of arthritis as the leading cause of disability;
- support persons with arthritis in accessing the resources needed to cope with their disease; and
- ensure that persons with arthritis receive the family, peer, caregiver and community support needed to facilitate successful self-management.

I. Arthritis in Illinois

A. Definition of Arthritis

The IAI defines “arthritis” as the more than 100 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 in 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: osteoarthritis, rheumatoid arthritis, fibromyalgia, systemic lupus erythematosus, juvenile rheumatoid arthritis, and gout. These six diseases are the focus for the *Illinois Arthritis Action Plan*. For more information on these, or other rheumatic conditions, please contact the appropriate agency listed in the “IV. Illinois Resources” section of this document.

B. Burden of Arthritis

State Data

The Behavioral Risk Factor Surveillance System (BRFSS) is a statewide telephone 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. The BRFSS results for 2002 show:

- 22.7 percent of the adult population in Illinois (2.1million persons) reported doctor diagnosed arthritis.
- 9.1 percent have possible arthritis.
- 40.9 percent felt some limitation in their activities because of joint symptoms.
- Of those reporting possible arthritis, 33 percent were limited in their activities because of joint symptoms.²

For more detailed arthritis-related data, please contact the Illinois Department of Public Health for a copy of the “*Illinois Arthritis Data Report: The Burden of Arthritis 2002*,” or it is online at www.idph.state.il.us/about/chronic/arthritis.htm.

Rural Populations

Although the population in rural areas of Illinois, as a proportion of the state’s population, has decreased in the past several decades, the proportion of Illinois residents 65 years and older is higher in rural Illinois than in urban areas. Based on the last census, 16 percent of the rural population was 65 years or older compared to 11 percent of the urban population.

Physician availability, or access to health care services, is defined as a ratio of primary care providers to population in a defined area. According to the IDPH Center for Rural Health, 84 of Illinois’ 102 counties are designated “rural.” Of those 84 counties, 78 are also designated, in whole or part, by the U.S. Department of Health and Human Services as Health Professional Shortage Areas. Residents of rural counties have a higher prevalence rate of arthritis than those living in other areas. Inadequate access to health care, lack of transportation systems and limited access to patient education and prevention services continue to be problems, as most arthritis education programs are based in metropolitan areas.

Persons with Disabilities

Almost 50 million Americans have a disability that limits their daily activities.⁴ For a significant proportion of persons with a disability, arthritis is the main cause of their limitation.⁵ In addition, a large number of persons with a disability is likely to have arthritis as a secondary cause of their limitation because persons with a disability frequently develop additional chronic conditions that are causally related to their primary disability.⁶ In fact, researchers reported that persons with a disability are more likely to have chronic conditions than those without a disability, and that the proportion of persons with a disability who have arthritis is three times higher than that for those without a disability.^{7 8} Thus, there is an urgent need to include this large, but underserved, population with a disability in ongoing intervention programs to prevent and control arthritis.

Future Arthritis Projections

With the aging of the U.S. population, the prevalence of arthritis is expected to increase. By the year 2030, an estimated one quarter of the projected total adult population, or 64.9 million adults, will have doctor-diagnosed arthritis, compared to the 42.7 million adults in 2002.⁹ Two-thirds of those with arthritis will be women. These estimates may be conservative as they do not account for the current trends in obesity, which also contributes to onset of disability and some rheumatic conditions.

Additional proven public health interventions that are easily accessible and affordable need to be made more available at the community level. Fewer than 1 percent of persons with arthritis who could benefit from such interventions receive them¹⁰. These interventions need to be designed to improve function, decrease pain and delay disability among persons with arthritis, particularly those at highest risk for functional impairment and disability. Because behaviors that place persons at risk for disease often originate early in life, the public health system should support healthy behaviors throughout a person's lifetime¹¹.

C. Challenges to Reducing the Burden

There are many challenges faced in reducing the burden of arthritis. Probably the biggest challenge is the lack of public knowledge about how large our current arthritis burden is and how much larger this burden will be as a result of the aging of our population. A second challenge is the limited number of medical and public health practitioners who are knowledgeable about arthritis and capable of helping individuals and populations affected by these illnesses. Finally, Illinois' diversity creates unique challenges for addressing the burden of arthritis. More than 22.7 percent of the state's population resides in the city of Chicago³; 84 of the 102 counties are designated rural areas; and there is enormous statewide racial and ethnic diversity. The IAI is addressing all of these challenges.

II. The Illinois Arthritis Initiative

History

In 1999, the Illinois Department of Public Health, Office of Health Promotion, was awarded funding from the U.S. Centers for Disease Control and Prevention (CDC) to develop a statewide program to reduce the burden of arthritis. Program staff were hired in the year 2000. The first goal of the program was to develop a statewide partnership of arthritis experts, including representation from academia, health and social service agencies and organizations, local health departments, rural health groups, agencies serving minority populations, the business/private sector, and persons with arthritis and their care givers.

The first Illinois Arthritis Partnership meeting was held January 13, 2000. The partners titled the program the “Illinois Arthritis Initiative” and created 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. To date, the Partnership has grown in capacity and number and provides invaluable support to IAI efforts.

Accomplishments: Years 2000 through 2005

Over the past five years, the IAI and partners have increased the capacity for statewide arthritis programming; increased awareness for arthritis diagnosis, treatment and self-management; and heightened the level of knowledge among policy makers about the need for state arthritis legislation.

Of the many accomplishments, highlights include the development of:

- a ***Self-Management Reach Report: 2000-2005*** (identifying growth of evidence-based Arthritis Foundation self-management courses and the CDC communication campaign over a five year period);
- a ***Self-Management Reach Report: 2005-2006*** (identifying growth of evidence-based Arthritis Foundation self-management courses and the CDC communication campaign over a one year period);
- the ***Illinois Arthritis Action Plan: 2000-2005*** (outlining objectives and strategies for statewide implementation);
- the ***Illinois Arthritis Data Report, 2000*** and the ***Illinois Arthritis Data Report, 2002*** (citing the burden of arthritis in Illinois);
- a ***Data Distribution Plan: 2005*** (identifying methods to disseminate data findings to appropriate groups through various channels);
- a ***Public Education Target Group Assessment*** (identifying target groups by geographic locations);
- a ***Pilot Survey to Measure the Extent of Arthritis Self-Management Efforts In Illinois*** (results of a survey which measured the extent of arthritis self-management programs in specific geographic areas, and the extent to which educators had difficulties and challenges in providing these programs);
- the ***Health Communication Strategies To Enhance Arthritis Self-Management Among Rural Illinois Residents: A Report of Findings 2002*** (findings from survey and focus groups); and
- the development of **region-specific fact sheets** for each of the 102 counties in Illinois.

Activities that have been accomplished include:

- increasing the availability and geographic dispersion of evidence-based Arthritis Foundation self-management courses;
- expanding services into additional rural and underserved areas each year;
- increasing the number of local health agencies implementing activities each year;
- enhancing data activities to continuously monitor state and county arthritis prevalence and quality of life;
- improving data collection systems to gather more comprehensive data regarding the number of self-management courses offered, their geographic location and participant completion status;
- enhancing the periodic collection of health outcomes data;
- assessing the correlation between arthritis and disability;
- developing state legislation to support reducing the burden of arthritis;
- increasing awareness among state and local policy makers of the need for state legislation to support additional arthritis activities;
- increasing awareness among local health providers regarding diagnosis, treatment, self-management opportunities and referral to Arthritis Foundation services; and
- providing annual national satellite conferences.

Partnering with the two state Arthritis Foundation chapters and their branch offices has proven to be mutually beneficial. The Arthritis Foundation staff have been instrumental in offering trainings; expanding self-management opportunities; and sharing resources, knowledge and experiences.

III. Future Directions: Years 2006 through 2009

A. Objectives and Strategies

Following are the rationale, objectives and activities for addressing arthritis in Illinois developed through the collaborative efforts of the Illinois Arthritis Partnership and its work groups. An annual work plan for achieving strategies will be developed by each respective work group.

Surveillance and Data Efforts

Rationale: Surveillance and data collection, analysis and monitoring can provide an important impetus to plan, develop, implement and evaluate program interventions and policies to address the burden of arthritis in Illinois.

OBJECTIVE **By 2009, maintain and expand an existing scientific database on the prevalence and impact of arthritis and related disability.**

- Strategy 1. Monitor changes in the prevalence of arthritis and its impact on disability and quality of life.
- Strategy 2. Identify disparities in arthritis prevalence in different populations, specifically in the project's core target groups.
- Strategy 3. Expand and promote utilization of state and county-specific arthritis-related BRFSS data.
- Strategy 4. Monitor progress toward achieving HP2010 arthritis-related objectives.
- Strategy 5. Update a comprehensive arthritis data work plan, on an annual basis, that assesses and evaluates existing data sources.
- Strategy 6. Develop a *Self-Management Reach Report* covering the period of October 2000 through June 2005, and annually through 2009.
- Strategy 7. Update the *Illinois Arthritis Data Report* every two years.
- Strategy 8. Update the *Data Distribution Plan* every two years.
- Strategy 9. Assist in the development of an *Illinois Arthritis and Disability Data Report*.
- Strategy 10. Explore continuation and expansion of cataloguing the geographic supply of arthritis programs and services.
- Strategy 11. Assess, prioritize and make provisions for the data needs of the Partnership and work groups, on an annual basis, for their projects and for the initiative's special projects.
- Strategy 12. Maintain a Surveillance and Data Work Group that meets a minimum of six times per year.
- Strategy 13. Evaluate surveillance and data strategies and actions on an annual basis.

Public Education Efforts

Rationale: Public education efforts will continue to focus on providing target groups with additional, and geographically convenient, evidence-based arthritis self-management opportunities; educational and awareness opportunities; and increased availability of resources and services, especially those of the Arthritis Foundation.

OBJECTIVE **By 2009, increase evidence-based arthritis self-management provisions and awareness and education opportunities for persons with arthritis and their caregivers.**

- Strategy 1. Utilize the *Target Group Assessment* to identify geographic dispersion of core target groups to more effectively implement arthritis self-management, awareness, education and intervention efforts.
- Strategy 2. Increase the number, and geographic dispersion, of leaders trained to conduct the Arthritis Foundation Exercise Program, Arthritis Foundation Aquatics and the Arthritis Foundation Self-Help Program.
- Strategy 3. Increase the number, and geographic dispersion, of local agencies implementing evidence-based self-management opportunities for persons with arthritis:
- in rural populations with limited access to care/services;
 - who are working and ages 35 to 65;
 - among minority and/or limited English-speaking groups; and
 - persons with a disability.
- Strategy 4. Track the number of participants and the number and geographic dispersion of arthritis self-management courses available and delivered throughout the state.
- Strategy 5. Increase public awareness of juvenile arthritis, especially among families, caregivers, school personnel and students to increase the rate of early diagnosis, knowledge of the disease, needs of youth with juvenile arthritis, availability of self-management provisions and available resources.
- Strategy 6. Increase the availability of arthritis-related resources to target groups to promote awareness of personal and family history, personal risk factors, signs and symptoms, importance of early diagnosis, ways to minimize preventable pain, self-management, treatment and value of arthritis prevention.
- Strategy 7. Partner with other chronic disease prevention and health promotion efforts to increase self-management opportunities, awareness messages, and education, including expanding methods to promote physical activity and nutrition/weight management as a form of arthritis management.
- Strategy 8. Maintain a Public Education Work Group.
- Strategy 9. Evaluate public education strategies and actions on an annual basis.

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 management, prevention and intervention activities.

OBJECTIVE **By 2009, increase appropriate resources and funding for statewide and local arthritis and arthritis disability prevention programs.**

- Strategy 1. Continue to create and sustain an increasingly effective coalition to promote aggressive state arthritis and arthritis disability awareness and prevention policies, including securing state funding for comprehensive arthritis activities.

- Strategy 2. Continue to increase the capacity (including human resources) of the state and local public health infrastructure to conduct surveillance/data collection, to provide evidence-based public and professional education, to increase the knowledge base that supports evidence-based arthritis public health practice, and to provide leadership in policy development that would facilitate arthritis and arthritis disability prevention activities.

- Strategy 3. Continue to identify strategies for increasing Illinois decision makers' awareness of the burden of arthritis and related disability as a public health issue.

- Strategy 4. Assist other work groups to address their prioritized legislative and policy issues.

- Strategy 5. Maintain a Public Policy and Infrastructure Work Group.

- Strategy 6. Evaluate the public policy strategies and actions on an annual basis.

Professional Development/Health Care Systems Efforts

Rationale: Professional development activities will focus on local health providers, local health educators; Arthritis Foundation (AF) staff and self-management trainers and leaders in local health departments/agencies, AF offices, social service agencies and schools of public health. Efforts will include raising the awareness of the needs of persons with arthritis, the importance of early diagnosis and treatment, resources available, the availability of AF self-management, referral to AF resources and potential effects of complementary and alternative medicine utilization by persons with arthritis.

OBJECTIVE **By 2009, provide professional development opportunities for local health care providers (local health departments, specific hospitals, etc.); Arthritis Foundation staff and self-management trainers and leaders.**

- Strategy 1. Conduct an annual assessment to identify professional development needs of target groups and prepare a report of findings.
- Strategy 2. Develop and implement professional development opportunities based on findings from the annual assessment.
- Strategy 3. Administer a pre/post-test tool to participants of each intervention provided, to assess changes in participant's perceived ability to address and/or refer for the needs of persons with arthritis.
- Strategy 4. Maintain and continue to develop partnerships between state and local health agencies, Arthritis Foundation offices and professional organizations to enhance the ability to provide professional development.
- Strategy 5. Provide continuing education credits for participants of professional development offerings.
- Strategy 6. Modify professional development efforts based on evaluation, including pre/post-test findings.
- Strategy 7. Maintain a Professional Development Work Group.
- Strategy 8. Evaluate professional development strategies and actions on an annual basis.

Program Management Efforts

Rationale: 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.

OBJECTIVE **Throughout the life of the project, enhance and maintain overall management activities to improve program components and operations.**

- Strategy 1. Throughout the life of the project, maintain existing partners and work group members and recruit others to serve on the Illinois Arthritis Partnership.
- Strategy 2. Increase the number of productive partnerships by two each year.
- Strategy 3. Maintain and expand an existing scientific database on the prevalence and impact of arthritis and related disability.
- Strategy 4. Continue to assess the reach, outcomes, processes and effectiveness of overall program operation and individual projects and work group efforts.
- Strategy 5. Throughout the life of the project, maintain and foster the relationship with the Greater Chicago Arthritis Foundation and the Greater Illinois Arthritis Foundation and their branch offices to assure local awareness and outreach of AF services and information.
- Strategy 6. Throughout the life of the project, utilize *Healthy People 2010* and *National Arthritis Action Plan* objectives as a guide for state arthritis programming.
- Strategy 7. Throughout the life of the project, maintain communication with other states involved with arthritis efforts to increase knowledge and enhance Illinois' initiative.

B. A Call to Action

The Illinois Arthritis Partnership has begun to address the burden of arthritis in this state, but much more needs to be accomplished in order to avert the arthritis disability “epidemic” that is forecasted to occur in the next 20 years as a result of the aging of our population and the increasing frequency of obesity. Further growth of the public, private, and voluntary partnership must occur, and increased public, private, and voluntary health agency resources must be devoted to partnership activities in order that the burden of arthritis is reduced for all populations in Illinois. The framework for success is summarized in this document. What is needed is the collective commitment of all involved to make these plans reality.

IV. Illinois Resources

Illinois Department of Public Health (printed materials, state reports, provide referral to the Arthritis Foundation and local health departments)

Illinois Arthritis Initiative

535 W. Jefferson St.

Springfield, IL 62761

217-782-3300

www.idph.state.il.us/about/chronic/arthritis.htm

Greater Illinois Arthritis Foundation (printed materials, support groups, self-management courses)

2621 N. Knoxville Ave.

Peoria, IL 61604

309-682-6600

www.arthritis.org

Greater Chicago Arthritis Foundation (printed materials, support groups, self-management courses)

29 E. Madison St., Suite 500

Chicago, IL 60602

312-372-2080

www.arthritis.org

Illinois Area Health Education Center/Western Office (access to rural populations, especially through telecommunications; provide professional development opportunities)

Broadway at 14th, Second Floor

Quincy, IL 62301

217-223-0452

www.ihec.org

Illinois Institute for Rural Affairs at Western Illinois University

(Research on health communication strategies specific to rural areas and demographic data)

518 Stipes Hall
1 University Circle
Macomb, IL 61455
800-526-9943
www.IIRA.org

Lupus Foundation of America, Illinois Chapter

(printed materials, support groups, Lupus lending library, "Living with Lupus" Grant Program, education seminars)

20 E. Jackson Blvd., Suite 1150
Chicago, IL 60604
312-542-0002 or 800-2 LUPUS 2
www.lupusil.org

University of Illinois at Chicago—Center for Health and Aging (“Fit & Strong” osteoarthritis physical activity/self-management program)

School of Public Health, Suite 400
850 W. Jackson Blvd.
Chicago, IL 60607-3025
312-996-1473
www.uic/depts/ovcr/hrpc/centers/rha_content.htm#links

University of Illinois at Chicago—National Center on Physical Activity and Disability

(On-line interactive information and printed materials on various physical activities for persons with a disability. Information may be available in alternative formats such as large print, Braille, voice recording, etc. upon request.)

Department of Disability and Human Development
College of Applied Health Sciences
University of Illinois at Chicago
1640 W. Roosevelt Road
Chicago, IL 60608-6904
800-900-8086 (voice and TTY)
www.ncpad.org

Citations

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⁹ 2002 National Health Interview Survey and U.S. Census Bureau as reported by U.S. Centers for Disease Control and Prevention. “Targeting Arthritis – Reducing Disability for 43 Million Americans.” (2005)

¹⁰ U.S. Centers for Disease Control and Prevention. “Projecting Prevalence of Self-Reported Arthritis or Chronic Joint Symptoms Among Persons Aged \geq 65 Years – United States, 2005-2030.” *Morbidity and Mortality Weekly Report* 52(21): 489-91. (2003)

¹¹ U.S. Centers for Disease Control and Prevention. “Public Health and Aging: Trends in Aging – United States and Worldwide. *Morbidity and Mortality Weekly Report* 52(06): 101-106.