

Arthritis & Disability
TOWN MEETING REPORT

DOES SOCIETY

*do enough,
care enough,
spend enough*



In a modest community setting in Columbia, Mo., 100 people gathered to talk about a disease that usually doesn't make headlines, doesn't attract many big-named stars as advocates, and usually isn't visible to most people despite its ranking as the nation's number one cause of disability.

Arthritis is a serious and sometimes fatal disease that affects tens of millions nationwide, but all too often people aren't receiving the care and social services they need.

What's wrong is that the public and medical professionals often don't have enough information about the disease's consequences and impact, and legislators, regulators and business leaders aren't devoting adequate resources to fund research, treatment, rehabilitation and health policy initiatives.

Town meeting participants included people with arthritis, elected officials, business leaders and medical professionals.



Working in focus groups headed by Rep. Vicky Riback Wilson and former governor Roger Wilson, Town Meeting participants looked for solutions to what sometimes seem like insoluble problems.

Caring enough to make the difference

To do what's right, 100 people convened to confront the burgeoning scientific, social and economic challenges that arthritis and disability pose for our nation. They included individuals with arthritis who cope with the disease every day; the physicians who provide their care; the occupational and mental health practitioners who help them maintain quality of life; and the legislators and public policy advocates who decide on how much society is willing to pay to address their concerns.

At a Town Meeting held in Columbia, Mo., in November 2002, these people spent a day working to achieve consensus and arrive at the

best way to meet growing needs in a health care system already facing ever increasing demands.

Their voices rang out as they set priorities, identified needs, and developed objectives and goals.

This report is a description of the consensus reached during the Town Meeting.

Designed to provide the public with open access to a freewheeling exchange of opinions, ideas, insights and complaints, its objective was to identify how to improve the lives of the more than 70 million Americans with arthritis.

Sponsored by the Missouri Arthritis Rehabilitation Research and Training Center (MARRTC), a national center funded by the National Institute on Disability and Rehabilitation Research (NIDRR), the Town Meeting was also hosted by the Missouri Arthritis & Osteoporosis Program and the Central Missouri Branch of the Arthritis Foundation.

In her keynote address, Cyndi Jones, director of the Center for an Accessible Society, a San Diego-based organization dedicated to increasing public awareness about disability issues, urged the participants to find solutions to what sometimes feel like insoluble problems.

"Do we, you and I — do we — have what it takes to change this? Do we care enough? Do we do enough? Do we spend enough?" she asked. "Today, today is the only day we have, and today the people at the table are the people we have. So today we have the opportunity to impact how research and programs for people with arthritis will take place over the next decade, if not over the rest of our lifetime. We can shape this, so let's get to it."

Throughout the day, attendees accepted this challenge by meeting in groups and then as a body to discuss the issues and reach agreement on how best to address the priorities. By the end of the day, a consensus emerged from those disparate voices identifying five priorities that if managed properly would ease, or possibly even end, the challenges of arthritis and disability for millions. Those priorities are:

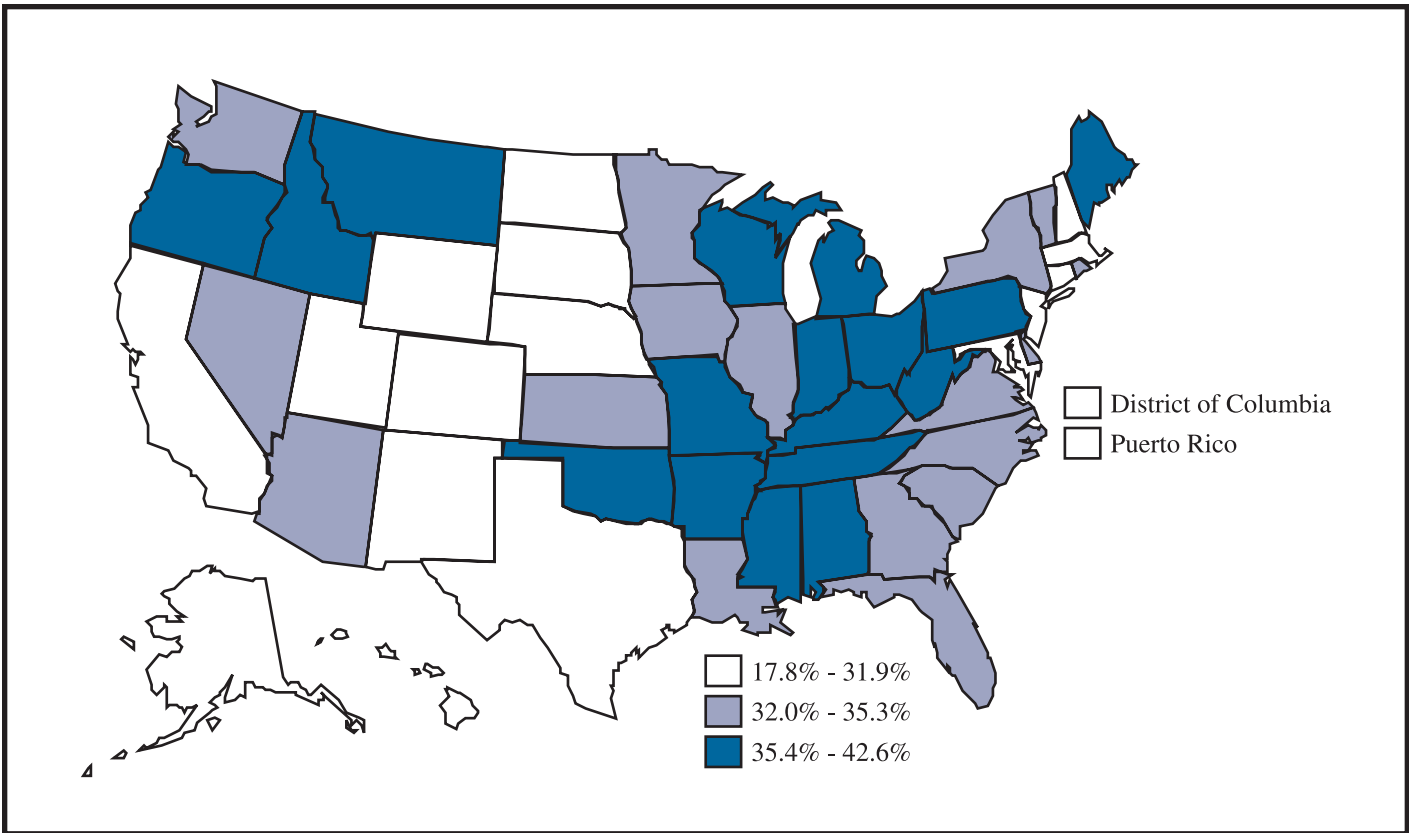
Awareness: For people to care enough, every segment of society needs to achieve a more profound understanding of the nature of arthritis and its impact on Americans.

Education: For everyone coping with arthritis and its symptoms — and for physicians, physical and occupational therapists, mental health practitioners and other healthcare workers — it is necessary to improve knowledge of how arthritis progresses and to assure access to the information and self-management skills that produce the best health outcomes and quality of life.

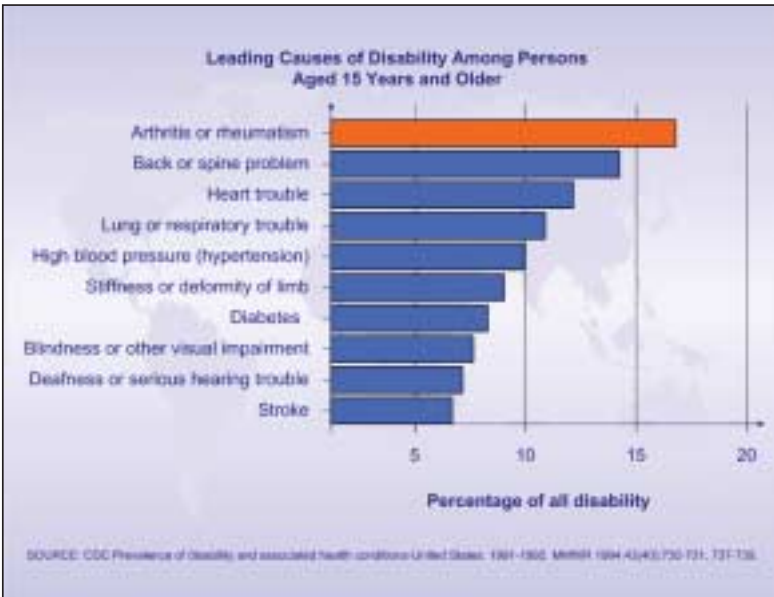
Treatment: Making certain that people with arthritis have access to a seamless continuum of care requires that we implement comprehensive, integrated health services models that assure early diagnosis and fulfillment of appropriate treatment and rehabilitation plans.

ARTHRITIS FACTS

- Arthritis is the No. 1 cause of disability in America.
- Arthritis affects an estimated 70 million Americans — nearly one of every three people.
- Arthritis comprises more than 200 diseases and conditions that affect joints, the surrounding tissues and other connective tissues. Three of the most common forms of arthritis are osteoarthritis, rheumatoid arthritis and fibromyalgia.
- Arthritis pain is not just something to endure. Research shows that pain and disability can be minimized with early diagnosis and treatment. Treatment can include medication, exercise, weight control, physical and occupational therapy as well as joint replacement.
- Arthritis also affects children; juvenile arthritis is one of the most common chronic illnesses of childhood, affecting about 300,000 children in America.
- The medical and social costs of arthritis total almost \$65 billion yearly — a figure equivalent to a moderate national recession.



Percentage of adults aged 18 years and older with arthritis/chronic joint symptoms by state/area in the United States.



commitment to battling arthritis by implementing initiatives that promote new advances in each of these areas.

One message was clear from the Town Meeting: Something needs to be done about the most disabling disease in America. And it needs to be done soon.

While modern medicine, groundbreaking research and laws ending discrimination against persons with disability have given people with arthritis better health outcomes and an improved quality of life, there are still important goals to achieve: new and improved treatments must be discovered, access to care must be assured, and the societal

Benefits: Private and public healthcare payers must revamp benefit programs to make certain the proper level of resources exists so that everyone can receive all the services they need.

Research: Increasing resources devoted to research will result in ongoing improvement in health care for people with arthritis and disability and will extend the hope that one day there may be a cure.

Town Meeting participants urged a renewed

impact of disability must be minimized or eliminated. If we fail to meet these objectives, the medical, fiscal and social problems associated with arthritis and other potentially disabling diseases will increase exponentially as the nation's population ages.

Will we care enough, do enough and spend enough?

Everyone attending the Town Meeting agreed it's time to decide that we will.

Awareness

A recent incident helped 60-year-old Ann Rash understand why it's important that people be aware of arthritis, its symptoms and its disabling effects. While on a shopping trip, a woman chastised Ann for parking in a handicapped zone. Although two decades of rheumatoid arthritis, including multiple joint replacements, left Ann's hands with signs of disability, the other woman failed to notice them. She also couldn't have noticed that arthritis had affected Ann's feet, too.

Ann's arthritis-caused disability is not highly visible unless someone looks closely. One of

ARTHRITIS is a significant health issue that deserves more support and resources. Everybody – national leadership, the public, medical professionals and patients – needs to recognize this.

the reasons arthritis symptoms and disability are often out of the public view is because they're not always apparent to others. Situations like the one in the parking lot symbolize the misunderstanding and insensitivity people with arthritis face.

The need to increase awareness topped the list of consensus statements drafted during the Town Meeting. For those who attended the conference, it was important that all segments of the community – the general public, medical providers, legislators and policymakers – understand that arthritis and the disabilities it causes require priority attention. People desperately need a comprehensive, integrated system of care and the resources to provide it. But to reach that goal they also need the country's leadership to recognize the dangers of not addressing the societal impact of arthritis and the dire public health consequences if they fail to act soon.

Ann is just one of 70 million Americans with arthritis, an illness that affects one of every three people, according to the Centers for Disease Control and Prevention. It's the nation's No. 1 cause of disability, and it's likely to get worse — a lot worse.

Arthritis rates will climb as the population ages. The disease affects people of all ages and races, but it is more common among women and older people, according to the CDC. For people aged 45 to 64, 42 percent have arthritis. By the time people reach their 50s and 60s,

more than half will ultimately be affected by arthritis. For people older than 65, the rate rises dramatically to nearly two-thirds. Nationally, 300,000 children have arthritis, according to the Arthritis Foundation.

Arthritis also takes a tremendous economic toll, one that is rapidly rising. In 2000, arthritis cost the nation \$124.8 billion, nearly two times the 1992 outlay of about \$64.8 billion. Of that \$124.8 billion, direct medical expenses accounted for more than one-third, with Americans spending \$42.6 billion for hospitalizations, doctor visits and medications. The other two-thirds, or \$82.2 billion, are the indirect economic costs of arthritis, including in large part lost wages.

The statistics show why health care professionals, policymakers and the public should make arthritis a top priority, but the disease's impact is also felt in human terms. Often affecting people in the prime of their lives, its prevalence is what makes arthritis the nation's top cause of disability. It interrupts careers when people are often most productive, and it interferes with responsibilities to families. The price of societal ignorance includes poorer medical outcomes, increased disability, inadequate resources to meet the healthcare needs of a growing population and higher costs later as society tries to play catch-up.

Then there are the intangible costs that can't be measured in dollars, such as chronic pain, depression and curtailed activity and lifestyle quality for individuals and their families. In many cases, this means people with arthritis lose their ability to do the simple things in life, the every day activities that can keep them independent and connected to their families and communities: shopping, laundry, cooking, making family arrangements and managing finances.

Increasing awareness about arthritis, therefore, is a crucial first step toward confronting this insidious disease. So what did those who attended the Town Meeting mean when they identified "awareness" as the top issue facing society when it comes to arthritis?

In many cases, some of the disability associated with arthritis is preventable, so it's important to give people the information they need to avoid developing the disability in the first place. A lack of awareness can mean that people who experience early symptoms won't take the necessary steps to manage the pain, injury and disability that can result from arthritis. It can also mean that those who seek treatment won't know how to access the best care or won't get the appropriate medical advice. Left untreated or poorly managed, arthritis can result in a

decline in mobility and independence.

Since it's a medical condition, awareness means knowing about the appropriate levels of care and keeping up-to-date on the newest medications and treatment regimens. It's potentially disabling, so people need to know about ways to slow the disease's progression, including appropriate medications, physical therapy, exercise and a healthy diet. Its prevalence also means we all have the responsibility to recognize that unless we devote the necessary resources to treating this illness, there could be long-term consequences that affect everyone.

The lack of awareness by employers and employees means people are performing jobs that can make their arthritis worse and increase the risk of disability. The Americans with Disabilities Act states that employers must make "reasonable accommodations" for people with a disability. For those with arthritis, these accommodations can be simply accomplished and often cost less than \$1,000, according to a study conducted by the Job Accommodation Network in 1990.

The lack of awareness among educators means children with arthritis may not be identified in sufficient time to get the help they need. Kids who are required to participate in school-related physical activity — such as running a 12-minute mile — could experience serious injuries or a worsening of their conditions if the disease isn't spotted.

The lack of awareness among healthcare providers can mean that people with arthritis may not get the specialty care they need to prevent the worsening of symptoms or the onset of disability.

The consensus of those who attended the Town Meeting was that awareness ultimately is about information and making sure the right people know the right facts about arthritis so that the right things can be done by the right people at the right time.

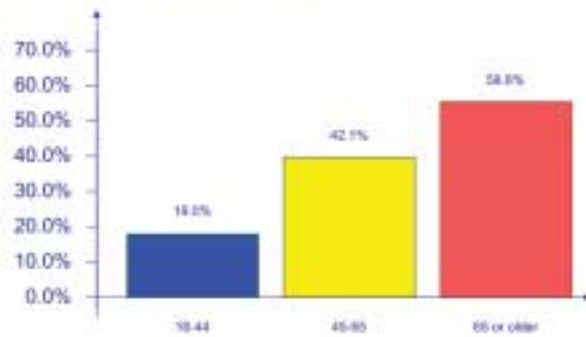
What is arthritis, anyway?

Arthritis is an umbrella term for more than 200 different conditions that affect joints and related tissues and, in some cases, internal organs as well. It is a set of complex, chronic diseases that may lead to disability and even increased incidence of death.

Children with arthritis are prone to a condition that can lead to blindness. In some forms of arthritis, such as lupus, the disease can also affect the nervous system, as well as the lungs and other organs. Some forms of arthritis have visible symptoms, but often its effects are hidden from view.

The common forms of arthritis are:

Prevalence of Arthritis or Chronic Joint Symptoms (CJS) Among U.S. Adults by Age Group Among U.S. Adults, 2001



SOURCE: Prevalence of self-reported arthritis or chronic joint symptoms among adults—United States 2001. *MMWR* 2002;51(42):948-950.

ARTHRITIS IN MISSOURI

■ **Missouri is one of the few states with regional arthritis centers. Seven regional arthritis centers offer exercise and self-help classes, support groups and work to educate the public about arthritis.**

■ **Based in Columbia, the Missouri Arthritis Rehabilitation Research and Training Center (MARRTC) is the nation's only federally funded, arthritis-related rehabilitation center. MARRTC's purpose is to provide national leadership to prevent and manage disabilities in people with arthritis and related diseases.**

People with arthritis critically need a comprehensive, integrated system of care and resources.

- **Osteoarthritis:** The most prevalent form of arthritis, osteoarthritis, or OA, affects about 21 million people in the United States or about 12 percent of the population.

- **Rheumatoid arthritis:** A common form of arthritis is rheumatoid arthritis, or RA. It affects about 2.3 million people, or about 1 percent of the population, mainly women.

- **Fibromyalgia:** This rheumatic illness affects about 3.7 million people in the United States, or about 2 percent of the population, most of whom are women. It is one of the most invisible forms of the disease: there is no swelling, only pain.

Education

Six years ago, Phyllis White realized something was wrong after experiencing severe fatigue and joint pain that made daily tasks such as caring for her young daughter and going to the grocery store a struggle. Her physician diagnosed rheumatoid arthritis and Sjögren's syndrome, a chronic inflammatory disease that causes dry eyes and mouth, and prescribed an appropriate treatment regimen. But Phyllis continued to experience recurring and worsening symptoms that made her feel depressed and hopeless.

A referral to a self-management education

program, where Phyllis learned about exercise, relaxation techniques, biofeedback and stress relief, gave her the skills to cope with the aches and pains and the demoralization her symptoms caused. Today, Phyllis is able to work part time teaching music at a preschool while fulfilling her role as wife and mother in a busy household. "I wish other people who have arthritis could go through the education program I had. I don't think I'd be the same person today if I hadn't."

Participants at the Town Meeting agreed that education must receive more attention and priority. People's health and quality of life

shouldn't be needlessly diminished simply because they don't know a better treatment is available or because they haven't learned the skills that could improve the quality of their lives. So, to make certain information is properly disseminated, the participants envisioned a constructive partnership between people with arthritis and the various health care professionals who treat or assist them. Implementing this collaboration would create an environment of shared responsibility that ensures everyone knows the information that is critical to quality care.

People with arthritis develop the ability to cope with their disease by understanding that adherence to medical advice and other elements of their care are important components of a suc-

cessful health outcome. "They will benefit from a specific type of education in which they learn and practice the skills they need to successfully manage their disease," says Marian A. Minor, P.T., Ph.D., chair of the Department of Physical Therapy at the University of Missouri-Columbia School of Health Professions.

Meanwhile, those individuals responsible for providing care must obtain the necessary training and ongoing education that assures they are giving advice and recommendations that conform to the most recent advances.

With arthritis, what people don't know may harm them. The illness, in all of its forms, is chronic and often progressive, so people with arthritis need to understand how to manage every aspect of their disease treatment, including medication, physical and occupational therapies and lifestyle choices. Research pub-

IMPORTANT THINGS TO LEARN ABOUT

ARTHRITIS

Common Symptoms of Arthritis

- Warmth and redness in a joint
- Swelling in one or more joints
- Stiffness around the joints that lasts for at least 1 hour in the early morning
- Constant or recurring pain or tenderness in a joint
- Difficulty using or moving a joint normally

Other Things to Know

- Exercise at appropriate levels can reduce pain and inflammation and improve function for people with arthritis.
- Self-management courses, such as the Chronic Disease Self-Management Program, can help prevent or delay disability for people with arthritis.
- Keeping healthcare providers up-to-date with the latest research and treatment information is a critical component of arthritis care.

TEACHING self-management skills to people with arthritis is among the most effective ways to improve their quality of life. Teaching health professionals about the latest advances in medical care significantly helps as well.

lished in the *Journal of the American Medical Association* bears out that “self-management education complements, rather than substitutes for, traditional patient education in supporting patients to live the best possible quality of life with their chronic condition.”¹

The chronic, unpredictable nature of the many types of arthritis means that the course of each person’s illness can vary. Developing treatment plans that meet individual needs is an important way to assure the best outcomes. Healthcare providers can offer the broad array of medical, therapeutic, social and psychological services people with arthritis need, while medications can also help alleviate symptoms. But managing this constellation of care requires that both providers and people with arthritis understand the variety of options available.

So education must include learning how to self-manage the disease so that individuals can work in partnership with their healthcare providers to develop the comprehensive, integrated treatment plan they need. Through self-management education, people learn how to “make day-to-day decisions about ... their illnesses,” according to the JAMA article. As the level of education rises, people with arthritis experience better health outcomes and more cost-effective treatment.

Improving the knowledge of those directly affected by arthritis, however, is only half of the equation. Every person needs to know the basic facts about arthritis, resources, available assistance and the importance of prevention, early diagnosis and treatment in order to improve long-term outcomes. As the population ages, the risk of developing arthritis will increase, but early knowledge about ways to prevent the onset or lessen the severity of the illness could mean billions of dollars of savings in avoidable healthcare costs.

Education also means that legislators and officials at all levels of government and health insurance company executives in the private sector need to know that neglecting to appropriate funds for information dissemination and programs designed to teach arthritis management skills has a cost, too. A failure to allocate sufficient resources for education will only lead to increased costs later, measured both in dollars and preventable disability.

Employers and benefits providers should



also have a better understanding of how integrated, comprehensive systems of care can improve productivity, create a healthier population and reduce overall costs.

For the general population, learning the basic warning signs of arthritis has the potential to prevent worsening illness or disability. For instance, research presented at the American College of Rheumatology’s 2002 annual scientific conference revealed that a mere three-month delay in the treatment of rheumatoid arthritis could inflict irreversible joint damage.²

Although arthritis cannot be cured, it can be treated. Today there are medications that can slow the progress of some forms of arthritis. Ongoing physical activity can alleviate its symptoms. But many of these findings are relatively new. So it’s imperative that educational efforts be directed toward patients, the general public, healthcare providers and benefits payers to assure they are constantly updated with the latest developments in arthritis care and treatment.

¹Bodenheimer, T., Lorig, K., Holman, H., Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *Journal of the American Medical Association* 288;2469-2475.

²Nell, V.P.K., Machold, K.P., Eberl, G., Stamm, T., Uffmann, M., Smolen, J.S. (2002). The benefit of very early referral and therapy with disease modifying antirheumatic drugs in patients with early rheumatoid arthritis. *Arthritis & Rheumatism* 46(9);S334.

Although arthritis cannot be cured, it can be treated. Ongoing physical activity can alleviate its symptoms.

Treatment

A child can still be in diapers when abnormal test results lead a doctor to suspect arthritis. When follow-up tests yield the same disturbing results, a referral to a pediatric rheumatologist may confirm the diagnosis that will present a host of challenges for a child growing up with juvenile arthritis in any of its myriad forms.

James Cassidy, M.D., a nationally recognized expert on juvenile arthritis, urges the immediate implementation of a comprehensive treatment program to impede the progress of a child's illness to minimize joint damage and

other negative effects. Care may include physical therapy, splints, frequent laboratory tests, and the latest medications.

While children still may exhibit symptoms of arthritis such as growth impairment, joint damage, or disability, they can still attend school and participate in other activities with proper care and attention. The key is to avoid early joint damage and the loss of mobility and range of motion, and to delay as long as possible the need for joint replacement surgery or other more complex treatments.

Making sure that every patient can obtain access to

integrated, comprehensive treatment was among the highest priorities established by the participants at the Town Meeting. Despite significant efforts over the years to improve access to a full range of care by federal, state and local governments, there are still too many people who won't get the attention they need and deserve.

There are a variety of complex reasons why people with arthritis and related disabilities often don't receive the appropriate interventions. In order for a system of care to work effectively it must include a carefully designed interaction between patients, physicians, other healthcare practitioners, educators, benefits providers and payers. As a result, some of the obstacles people with arthritis face are the same ones experienced by many other Americans with chronic health conditions who may not

have adequate health care or pharmaceutical benefits, or who don't have the information or the resources that would promote healthier lives.

"For people with arthritis, the goal is to reduce both the acute and chronic aspects of the disease," says John Klippel, M.D., the medical director of the Arthritis Foundation in Atlanta, Ga. Implementation of an integrated, comprehensive treatment strategy designed for each individual's needs addresses both elements by mitigating the immediate symptoms and progression of the disease while reducing or eliminating its future consequences and impact. For the individual, this means preventing or diminishing disability, minimizing work loss, limiting joint damage, avoiding surgical intervention and improving overall health outcomes. For society, it reduces the increased costs of health care and related expenses that result when individuals become seriously ill and disabled, and it improves productivity in the workplace and in the home.

Early access to a physician who can diagnose arthritis or other potentially disabling diseases is the first step toward ensuring people receive the medical care they will need to thwart either preventable disability or aggravation of symptoms. It's important that patients understand that ignoring ongoing pain or other impediments to movement can have serious consequences. One-fifth of people with chronic joint symptoms, which can signal arthritis, have never seen a healthcare provider for their symptoms, according to a report from the Centers for Disease Control and Prevention.¹

Once people are diagnosed with arthritis, they should receive a complete assessment of their illness and then implement a treatment intervention that coordinates multiple levels of care depending on their individual needs. This could involve any number of services, including referral to specialty medical care, the prescription of appropriate medications, commencement of physical, occupational and other rehabilitation therapies, self-management education, nutritional guidance and mental health and social services. But a major problem that still requires a better solution is determining who will coordinate that care for patients and assuring that whoever manages treatment and rehabilitation is fully informed of the latest advances.

"It's not clear that there is someone to coordinate and drive this kind of care and interaction for people," Klippel says. Often health care providers don't have the time, skills, information or financial resources to offer the kind of

EVERY PERSON with arthritis should have access to an integrated, comprehensive treatment program that maximizes health outcomes and minimizes the likelihood of disability or the erosion of quality of life.

seamless, integrated illness management that would yield the best outcomes.

Many people get involved in one part of the care but are not brought into the other kinds of care. “It’s not clear that the way the healthcare structure exists that primary care physicians would even be in a position to coordinate this kind of care. And the lack of someone to coordinate this kind of care is an obstacle.”

There’s still much to be done to elevate physician training to a level that would support an improved care model. The 1999 National Arthritis Action Plan,² developed by the Centers for Disease Control and Prevention and others, recognized that primary care physicians are the “first line of defense for the early diagnosis and appropriate management of arthritis.” Despite that important role, however, medical schools vary in the emphasis they give to rheumatology training. As a result, the gatekeeper is often not fully prepared to coordinate care in a meaningful way.

“General practitioners and family physicians may have little training in arthritis and may not, therefore, be able to make an early and correct diagnosis and institute appropriate therapy,” says Gordon Sharp, M.D., a rheumatologist and former chair of the Missouri Task Force on Arthritis and the Missouri Arthritis Advisory Board. “Even some rheumatologists are not aware of the use of exercise and the importance of self-help courses.”

Systemic issues discourage medical students from choosing careers in rheumatology, according to the American College of Rheumatology. Complex reimbursement rules and reductions in government funding for training have resulted in a 40 percent drop in the number of physicians entering medical training since 1992. “This translates to a decreased number of practicing specialists at a time when patients will need them most,” the ACR says in a position paper.

Ultimately, we need to make “health care



easier for people,” says Klippel. Depending on the nature of the arthritic condition, people may have significant difficulty gaining access to the range of care they may need. There have been important advances in all of these musculoskeletal disease areas that have not been well coordinated or utilized, Klippel concedes. “There’s a huge need to think along these lines.”

¹Center for Disease Control. (2003). Adults who have never seen a health-care provider for chronic joint symptoms - United States. *Morbidity and Mortality Weekly Report* 52:416-419 at <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5218a4.html>.

²Arthritis Foundation, Association of State and Territorial Health Officials, Center for Disease Control and Prevention. (1999). *National Arthritis Action Plan: A public health strategy* at <http://www.cdc.gov/nccdp/pdf/naap.pdf>.

People with arthritis can benefit from access to self-management programs that can reduce stress and improve their quality of life.

Benefits

Sara Walker, M.D. has provided care for people with arthritis for more than three decades. A leader in her field, both as a clinician and a researcher, she is a past-president of the American College of Physicians, a 115,000-member organization that is among the nation's largest medical societies. Even though the best outcomes result from comprehensive, integrated programs of care, she says the lack of insurance or public healthcare resources is the main obstacle keeping people from receiving the medical attention they need.

ACCESS to an integrated, comprehensive system of care for children and adults with arthritis depends upon a benefits system that assures private and public resources are available to those who need them.

Town Meeting participants also concluded that the lack of access to specialty care physicians, physical and occupational therapy providers, mental health services, educational programs, medications and other ancillary supports most often results from the simple fact that there's no money to pay for them. As a result, their call for improved insurance and other resources for those with arthritis emerged as a

high priority.

While the United States spends more on health than any other nation in the world, there are still vast numbers of people who cannot access care because the costs are beyond their reach. With 45 million Americans uninsured, people with arthritis are more likely than others to lack the coverage that would provide the medical, social and educational services they need. A report by Families USA,¹ a research organization based in Washington, D.C., found that the disabling effects of arthritis, and the resulting high unemployment levels, meant that individuals didn't have the workplace benefit plans that are the primary source of health care coverage for Americans. While federal legislation mandated that insurers issue policies to those leaving the workplace, persons who are chronically ill often can't afford health insurance once they leave their jobs or otherwise lose entitlement to employer-paid benefits.

The result is a vicious cycle that yields

poorer health outcomes, adds to costs and inflicts more anguish on those people who must also contend with the potentially disabling effects of arthritis. According to the Families USA report,¹ people with arthritis who are uninsured:

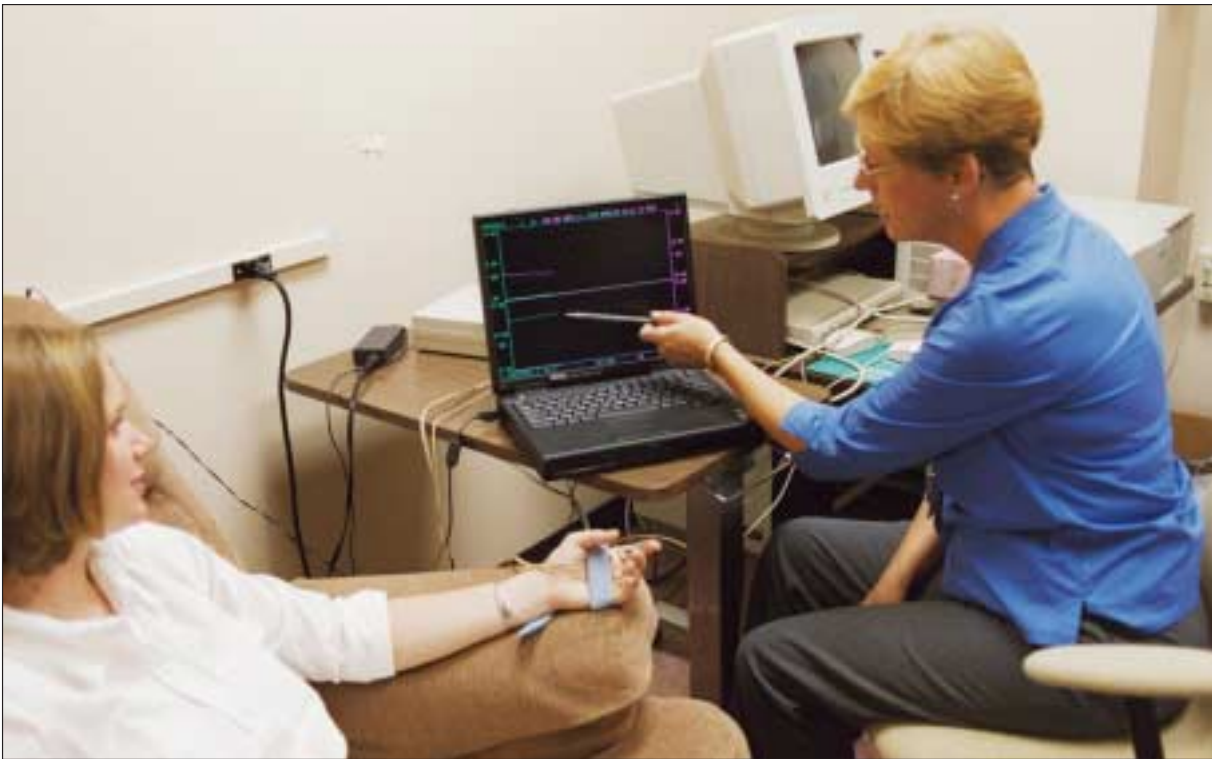
- make 27 percent fewer visits to their healthcare providers than those who are insured.
- are more than 3.5 times as likely to lack a usual source of care compared to people who have coverage.
- are five times more likely to receive no prescription medicines than those with health benefits.
- are two times more likely to not receive necessary lab tests within any given year than those whose care is reimbursed by insurance.

People who are underinsured also end up with inadequate healthcare and are often denied access to a wide array of services that could improve their conditions. Ill-conceived exclusions and limitations in health insurance policies and benefits programs, meanwhile, have an adverse effect on the range of treatment options available.

Kris Hagglund, Ph.D., associate dean of health policy at the University of Missouri-Columbia School of Health Professions has researched access to care issues and says that people are often kept from receiving alternative medicine, mental health services, rehabilitation therapy, medical equipment, primary and specialist physician care, prescription medications and inpatient hospitalization. Insurers also often fail to cover other services that have proven benefits. For instance, self-management programs that can help alleviate pain and decrease physician visits are often not eligible for reimbursement.

Rather than managing the cost of care, restrictive provisions in insurance policies often impose obstacles that have the opposite effect. There are a variety of negative consequences, Hagglund says, including pain, decreased function and a potential for further impairment that can increase health care and other societal costs in the long term.

Government-sponsored reimbursement programs are also often shortsighted when it comes to deciding who will receive benefits. For example, even when people meet poverty level guidelines, they must have dependent children, be over the age of 65 or satisfy a strict permanent disability test to qualify for Medicaid. Those hurdles mean that many people without the resources to purchase health insurance are either left without coverage or are underinsured. Meanwhile, many Medicare recipients don't



have the resources to purchase the medications that would alleviate arthritic symptoms or manage other comorbid illnesses.

Ultimately, Congress and the various states will need to legislate reforms to the nation's healthcare system so that everyone, including those who have arthritis and other chronic conditions, receive the care they need, Hagglund says. In 1999, the Atlanta-based Centers for Disease Control and Prevention published the National Arthritis Action Plan.² Its goals included: promoting arthritis awareness; improving surveillance and research to firmly establish the illness's prevalence and the outcome effects of treatment programs; enhancing communication and education efforts; and developing programs, policies and strategies to encourage prevention, early diagnosis and appropriate levels of care.

The CDC action plan urged modification of healthcare systems to help meet these objectives. "Existing healthcare systems, which were built around the need for acute care, are not well structured to meet the needs of people with arthritis and other chronic diseases" the report says. But implementing necessary reforms depends on educating leaders in all branches of government "about arthritis's effects on society and the success of intervention programs" so they can recognize and understand the importance of developing arthritis-related policies.

In the current era of state and federal budget crises, concerns over the availability of

resources make it as important as ever to communicate the long-term costs of short-term savings. For instance, the Missouri Arthritis & Osteoporosis Program, which was established in 1984, used its funding over the years to create seven regional arthritis centers located across the state. These centers offer the public information, support groups and self-management classes, but their ability to continue is threatened by the prospect of dwindling government support. In 2003, Missouri's Juvenile Arthritis Care Coordinator program, which assisted 4,000 children with arthritis, closed its doors after budget cuts.

Vicky Riback-Wilson, who attended the Town Meeting while a member of Missouri's House of Representatives, recognized the need for continuing support despite the current fiscal problems. "It is in the state's best interest to keep funding for arthritis strong because arthritis so dramatically affects the quality of life for people in the state," Riback-Wilson says. "If the programs we fund can keep people at their jobs, in their families and able to be a part of the community, then that's a good investment for the state."

¹Families USA. (February, 2001). *Getting less care: The uninsured with chronic health conditions*. Families USA Foundation. Washington, DC. Families USA Publication No. 01-102 at <http://familiesusa.org/site/DocServer/gettingless-care.pdf?docID=824>.

²Arthritis Foundation, Association of State and Territorial Health Officials, Center for Disease Control and Prevention. (1999). *National Arthritis Action Plan: A public health strategy* at <http://www.cdc.gov/nccddphp/pdf/naap.pdf>.

People diagnosed with arthritis should receive a complete assessment of their illness and then have access to treatment that is right for them.

Research

Despite more than two decades of research looking for the molecular key to autoimmune diseases, Robert Hoffman, D.O., professor and director, Division of Rheumatology and Immunology, University of Miami, says there's still much to learn before people with arthritis can hope for a cure or benefit from improved treatments. More research dollars will need to be devoted to exploring the complexities of arthritis, Hoffman says, at a rate consistent with the number of people affected by the disease.

In 2003, for instance, the National Institutes of Health (NIH) appropriated more than \$2.01 billion for heart disease research, an amount almost six times the \$380 million dollars devoted to arthritis.¹ Unfortunately, this disparity continued a trend. NIH funding for heart-disease research increased 48.5 percent between 1995 and 2000, while funding for arthritis increased only 31.4 percent.

Meanwhile, according to recently released statistics from the Centers for Disease Control and Prevention, heart disease now affects approximately 61 million people, compared to the approximately 70 million individuals with arthritis. Using disability as a measure, arthritis ranks first nationally, while heart disease ranks third.

The disparity in funding, says Marian Minor, Ph.D., P.T., an international expert on arthritis, results from a misunderstanding of the impact of arthritis. The illness is often incorrectly viewed as nonfatal, unlike heart disease or cancer, and is associated with normal aging rather than being viewed as a true disease.

While the CDC recorded 709,894 deaths due to heart disease in 2000, it listed no deaths resulting from arthritis for the same period. Yet research refutes the perception of arthritis as a nonfatal illness. Findings published in the *Annals of Rheumatic Diseases* showed that women with rheumatoid arthritis who test positive for rheumatoid factor face a risk of death equal to or greater than that associated with hypertension, heart disease or cancer.² Several other studies during the past decade have demonstrated increased mortality rates in people

with rheumatoid arthritis and have shown that people with severe forms of the disease may die 10 to 15 years earlier than expected.³ Other rheumatic diseases such as systemic lupus erythematosus, systemic sclerosis and systemic vasculitis also have a significant risk of mortality.⁴

While the incidence of arthritis does increase with age, the disease affects all age groups. Nationwide, there are 300,000 children with arthritis according to the Arthritis Foundation. In Missouri alone, there are 4,000 children with some form of juvenile arthritis.

Town Meeting participants decided that efforts toward preventing, curing and alleviating the effects of arthritis were a priority and that more research funding should be dedicated to improving treatment methods, reducing mortality and lessening the growing economic impact upon society. In their consensus statements, participants also urged federal research funding be spent on creating interim solutions that develop and foster comprehensive educational and rehabilitative programs. Research efforts should also focus on improving quality of life, reducing deaths that result from secondary conditions and slowing the progression of the disease processes of arthritis. For example, people with arthritis are more likely to have comorbid diseases such as high blood pressure, elevated blood cholesterol and diabetes than people without the illness, according to the Missouri Arthritis Report 2001.

Currently, the main focus of NIH funding is on the biomedical aspects of arthritis: finding out why the immune system loses its normal regulatory controls leading to autoimmune illnesses such as rheumatoid arthritis and lupus; why cartilage degenerates and leads to osteoarthritis; and why bones thin, causing osteoporosis. Another priority of NIH funding is genetics and determining why some people seem to be prone to developing certain forms arthritis. Finally, the NIH also supports clinical trials that search for new and more effective medications to treat arthritis.

So what else is needed? Town Meeting participants say that research should stress quality-of-life and long-term outcomes with an increased emphasis on calculating the cost offsets achieved by preventing disability. These goals mirror those outlined in the CDC's National Arthritis Action Plan and the Missouri Arthritis & Osteoporosis Program's State Plan for 2002-2007.

"Of course, we all want to find the cause and the cure — that is what we all hope will happen. But in the meantime, there are millions of people who already have arthritis and there

BETTER funding for research will lead to improved health and quality-of-life outcomes for millions of people.

needs to be more evidence to support treatment and rehabilitation,” says Minor. Since the 1980s, Minor’s work has been funded mainly by the Arthritis Foundation and the U.S. Department of Education’s National Institute on Disability and Rehabilitation Research (NIDRR), yet she and others say that funding from these sources cannot make up for the nationwide disparity between funding for arthritis and funding for other diseases.

“Very little [NIH funding], less each year, goes to quality-of-life studies that examine how to improve the lives of people with arthritis,” says Minor. “We know too little about how to minimize disability. We don’t have long-term studies of the benefits and possible harms of exercise or what kinds of exercise are best for different types of arthritis.”

Addressing this disparity requires a reassessment of how research dollars are allocated within the U.S. Department of Health and Human Services, which funds both the NIH and the CDC. The NIH, which predominantly sponsors biomedical research, received \$28 billion for fiscal year 2004, while the CDC, which emphasizes prevention and a coordinated, population-based strategy, received \$7 billion of the department’s \$548 billion budget.⁵

The CDC’s National Arthritis Action Plan calls for epidemiological surveillance and research that will better quantify the prevalence of arthritis and the factors that affect its impact on the population. Already, this emphasis is yielding important information, including updated figures released in 2002 that demonstrated that double the number of people than previously identified — one in three, rather than one in six — have the disease. Future research should generate new prevention strategies to minimize disability and improve quality of life by creating new treatments and improved rehabilitation programs.

Considering that more than half the people with symptoms of osteoarthritis and nearly three-quarters of those with rheumatoid arthritis report work-related disability, the rationale for this research lies in finding better ways to keep people productive. As for quality of life, 35 percent of people with arthritis have a loss of mobility and 17 percent cannot perform, without assistance, activities of daily living — walking across a room, dressing, bathing, eating, using the toilet and moving from a bed — so finding ways to help them is a critical need, too.⁶

Ultimately it is research, and its potential for a cure and improved health and life quality outcomes, that offers hope to the millions who have arthritis.



More research dollars are needed to explore the complexities of arthritis, which affects 70 million people.

¹National Institutes of Health and the Department of Health and Human Services. *Estimates of Funding for Various Diseases, Conditions, Research Areas*. Last update 8/17/04 at <http://www.nih.gov/news/fundingresearchareas.html>.

²Mikuls, T.R., Saag, K.G., Criswell, L.A., Merlino, L.A., Kaslow, R.A., Shelton, B.J., et al. (2002). Mortality risk associated with rheumatoid arthritis in a prospective cohort of older women. *Iowa Women’s Health Study. Annals of Rheumatic Diseases* 61:994-996.

³Anderson, R.J. (2001). Rheumatoid arthritis: Clinical and laboratory features. *Primer on rheumatic diseases* (12th ed.). In J.H. Klippel (Ed.). Atlanta, GA: Arthritis Foundation.

⁴McCarty, D.J., Koopman, W.J. (1993). *Arthritis and allied conditions: A textbook of rheumatology* (12th ed.). Philadelphia, PA: Lea and Febiger.

⁵U.S. Department of Health and Human Services. HHS: What we do. Last update April 11, 2004 at <http://www.hhs.gov/about/whatwedo.html>

⁶Dunlop, D.D., Manheim, L.M., Yelin, E.H., Song, J., Chang, R.W. (2003). The costs of arthritis. *Arthritis Care & Research* 49:101-113.

Outcomes

Despite the dramatic advances over the past decade that have provided new treatments and medicines for people with arthritis, there's still much to be done. Even though arthritis is the nation's most disabling illness, it is often hidden from public consciousness because it is stereotyped as a natural consequence of aging rather than a "real" disease. As a result, there are

COLLABORATION among non-profit organizations, academic institutions, public health agencies and private organizations is needed to meet the challenges of arthritis and its burgeoning consequences.

still millions of people of all ages who don't receive access to adequate care at an affordable cost. Poor health outcomes and deterioration of quality of life can only be addressed by building a comprehensive, integrated health care continuum that assures an appropriate level of intervention based on each individual's needs.

"The Town Meeting was an excellent opportunity for persons with arthritis, their health care providers, and others in the community to crystallize their thoughts and to express their views in the public health context," said Jerry C. Parker, Ph.D., a professor of physical medicine and rehabilitation at the University of Missouri-Columbia. He is also the director of the Missouri Arthritis Rehabilitation Research and Training Center, the organizer of the Town Meeting, and the associate chief of staff for research and development at the Harry S. Truman Memorial Veterans' Hospital.

The consensus statements drafted by the participants urged a renewed effort to enhance awareness, education, treatment, benefits and research as a way of advancing arthritis care. "These consensus statements will have tremendous value to government leaders and public health officials because they come straight from the hearts of concerned citizens themselves, and 70 million of these concerned citizens have arthritis," Parker said.

Government and public health oriented organizations have already plotted the direction the country must take in order to provide improved health outcomes and quality of life for

people with arthritis. The National Arthritis Action Plan of 1999, prepared by the Arthritis Foundation, the Association of State and Territorial Health Officials, and the Centers for Disease Control and Prevention, provides a clear picture of the objectives that must be attained to meet the growing needs.

Meanwhile, the Healthy People 2010 initiative, generated by federal agencies, and an alliance of more than 350 national membership organizations and 250 state health, mental health, substance abuse, and environmental agencies, has established a full set of objectives to alleviate the consequences of arthritis, osteoporosis and chronic back conditions.

At the state level, reports like Missouri's *Fight Against Arthritis & Related Conditions*¹ reflect the ongoing collaboration between non-profit organizations, academic institutions, public health agencies and private organizations that work together to meet the challenges of arthritis and its burgeoning consequences.

The action plan, which will carry Missouri's efforts through 2007, mirrored the aims and objectives urged by Town Meeting participants.

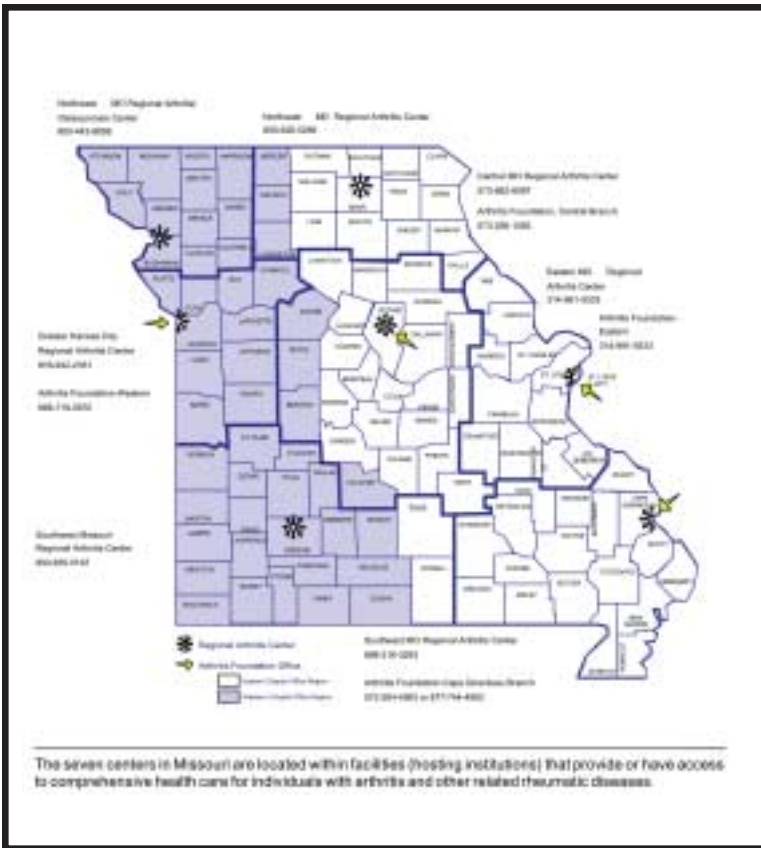
"It was exciting to see that the consensus statements of the Town Meeting participants were in agreement with the State of Missouri Arthritis Action Plan and reaffirmed that these state planners are heading in the right direction," said Gordon Sharp, M.D., a rheumatologist who helped develop the plan, and former chair of the Missouri Task Force on Arthritis and the Missouri Arthritis Advisory Board.

"In states that have yet to develop such plans, persons with arthritis, arthritis health professionals and other interested citizens may wish to hold Town Meetings to build consensus and advocacy for developing similar state-wide programs."

The larger question, however, still remains unanswered. Will we care enough, do enough and spend enough to make those plans turn into realities for people with arthritis?

The Town Meeting participants committed to doing what it takes to get the work done. But it will also take the commitment of the broader community, too, the kind of undertaking that challenges a great nation to do what is right to meet the legitimate needs of all its citizens.

¹Ankeney, ME, Beatty, VA, Kabeer, N. (2002). Missouri's Fight Against Arthritis & Related Conditions: A State Plan for 2002-2007. Sharp, G, Helmick, C., Ziegler, B, Arndt, B, Deshpande, A, Markenson, D, Shea, A (Eds). Missouri Department of Health and Senior Services, Missouri Arthritis and Osteoporosis Program. <<http://www.dhss.state.mo.us/maop/manual/stateplan.pdf>>



In fiscal year 2000, Congress made available \$12 million to initiate a national arthritis prevention program, with 38 states receiving funding for arthritis programs.





Missouri Arthritis Rehabilitation Research and Training Center

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