

# THE OREGON ARTHRITIS ACTION PLAN



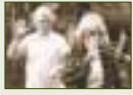
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*Optimizing the quality of life  
for Oregonians affected by arthritis.*

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OREGON ARTHRITIS COALITION  
JANUARY 2006

## ON THE COVER



*Carol, Laura and Lynelle teach Sun style Tai Chi,*

*which was designed to improve the quality of life for people with arthritis. This style is particularly effective for people with arthritis because it includes agile steps and exercises that may improve mobility, breathing and relaxation.*

---



*Mt. Hood overshadows a Parkdale area barn.*

*The local economy in Hood River County is Agriculture, food processing, forest products and recreation. Population is 20,5000 (2003 census).*

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*At 80, Mr. Gladstone has osteoarthritis in his knee and shoulder,*

*but his outlook on life is filled with humor and a great attitude. Mr. Gladstone keeps his joints going with his morning walks and gardening in the summer, growing his tomatoes and pruning his flowers. His favorite neighbor, Leo the cat, keeps him on his toes with regular visits.*

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*Portland's scenic skyline borders the Willamette River*

*and its many bridges. Multnomah County is urban and its economy diverse. Population 545,140 (census 2003).*

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*Laughing and having fun in the water are not only therapeutic*

*for the joints, but also for the soul. Portland's Matt Dishman Community Center has an array of water classes for everyone.*

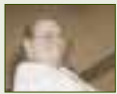
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*A farming field near Ashwood, Jefferson County. The local*

*economy in Jefferson County is agriculture, forest products and recreation. Population is 19,900 (2003 census).*

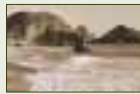
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*Barbara has fibromyalgia and knee osteoarthritis,*

*she exercises five times a week for 15 minutes to loosen things up and rides the stationary bike three times a week for 30 minutes, to limber up her knees and exercise her arms to help with weight loss.*

---



*Long Ranch Beach, southern coast, Curry County. The*

*local economy in Coos County is forest products, agriculture, commercial and sport fishing, recreation and tourism. Population is 21,100 (2003 census).*

---



*Six years ago, Marian broke out in an itchy rash all*

*over her body. Her joints became affected; she was unable to use her hands. The arthritis spread to her jaws, and she had difficulty eating. Eventually she was put on steroids, and her condition improved.*

*This spring, Marian was able to compete with her school's track team. Because of the stress on her joints and the pain and fatigue she experienced, she was unable to train like her teammates, lifting weights or running great distances. Instead, she set her own pace.*

*This year, Marian placed 7th in the high jump at the Oregon state track meet—as a sophomore. According to Marian, “When I’m jumping, I really don’t think about being sick.”*

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OREGON ARTHRITIS COALITION  
2006

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## OREGON'S ARTHRITIS ACTION PLAN

### WHERE WE'VE BEEN...

Since 1999 Department of Human Services, Public Health has received funding from the Centers for Disease Control and Prevention (CDC) to staff an Arthritis Program that could develop population-based approaches to assess and address arthritis in Oregon. In partnership with the Oregon Chapter of the Arthritis Foundation and the Arthritis Advisory Council, a statewide plan was developed and published in 2001.

The 2001 Oregon Arthritis Action Plan was built on the National Arthritis Action Plan and contained goals, objectives and strategies to achieve the mission of *"Optimizing the quality of life for Oregonians affected by arthritis."*

With the release of the 2001 plan, the Arthritis Advisory Council decided to sponsor the development of an Arthritis Coalition with broader representation from organizations and individuals interested in implementing strategies from the Oregon Action Plan. Coalition members have been involved in three major activities: 1) increasing the number of community leaders trained to provide the Arthritis Foundation Exercise Program, 2) promoting physical activity through radio ads and print materials using CDC's campaign materials "Physical Activity. The Arthritis Pain Reliever," and 3) updating and rewriting the arthritis chapter of the Ensuring Quality Care (EQC) manual used in training providers for Oregon seniors living in adult foster homes.

With the closing of the Oregon Chapter of the Arthritis Foundation in 2003, the Arthritis Coalition lost a valuable partner. However, the national office of the Arthritis Foundation and a Pacific Northwest Chapter, including Oregon, Washington and Alaska established in January 2006, have stepped forward and are demonstrating their commitment to improve the quality of life for people with arthritis in Oregon.

### WHERE WE ARE GOING...

Collectively as a Coalition there has been an explosion of synergy that has brought together new partners with a variety of different backgrounds and experiences to move this plan in a new direction. The current Coalition has come together to create a plan that opens up new possibilities of resources and joint partnerships to provide successful educational tools and programs in Oregon.

The 2006 Action Plan builds on the framework of the existing plan, but expands the vision with the addition of new partners and a larger scope of work. The Coalition made a decision to focus on goals relating to improving the lives of people with arthritis and also goals addressing those who are at risk for developing arthritis. Looking at the generational spectrum of people's lives is important for the prevention and proper treatment of arthritis. The plan's goal is to expand awareness, education and resources to everyone in Oregon and touch as many people's lives as possible.

New elements in the 2006 plan include a focus on:

- Children and families in addition to older adults
- Prevention messages and education
- Partnering with physical activity and nutrition programs
- Expanding efforts to monitor the impact of arthritis in Oregon

The planning process created new goals, objectives and strategies for the plan, and made sure to include inspiring stories and content throughout to highlight already existing programs. The new plan reflects the continuing growth in awareness and commitment to addressing arthritis in Oregon, and provides direction as we work collaboratively to *"Optimize the quality of life for Oregonians affected by arthritis."*

## ARTHRITIS OVERVIEW

**A**rthritis is a condition that we associate with our grandparents, or an elderly neighbor but in fact, arthritis can affect all ages. Nearly 65% of Oregonians with diagnosed arthritis are under the age of 65. These statistics do not include children. We know that 27% of adult Oregonians have arthritis and that 22% have chronic joint symptoms.<sup>1</sup>

Arthritis is an umbrella term that is used to encompass over 100 different types of *rheumatic disease* (describes a disease that involves the joints or related tissues and causes chronic pain and limitation of joint movement). Osteoarthritis, which is linked to trauma to the joints, is the most common kind of arthritis, affecting nearly 21 million Americans.

This action plan addresses 5 key goals.

### GOAL NO. 1

Increase awareness of arthritis.

### GOAL NO. 2

Prevent arthritis whenever possible.

### GOAL NO. 3

Increase the number of self-management educational resources.

### GOAL NO. 4

Expand the availability of educational and community-based resources.

### GOAL NO. 5

Monitor the impact of arthritis.

The Action Plan is a road map to guide the activities of the Coalition and local community organizations for the next 5 years. It is important to measure the progress toward these goals in order to identify barriers and successes along the way for future planning.



**GOAL NO. 1  
INCREASE AWARENESS  
OF ARTHRITIS**

**OBJECTIVE NO. 1**

*Increase public awareness of the cost, health impact, and prevalence of arthritis among children and adults.*

**Strategies:**

1. Develop a media campaign that addresses the cost, health impact and prevalence among children and adults that can be adapted to various audiences.
2. Contact and recruit legislators, decision-makers, health systems, insurers, and private industry to recognize the need to fund programs that increase the availability of resources for people with arthritis.

**OBJECTIVE NO. 2**

*Increase the awareness of arthritis services available throughout Oregon.*

**Strategies:**

1. Develop a resource guide that can be made available to the public.
2. Collaborate with local healthcare and social service agencies to provide information about community resources for people with arthritis.

**GOAL NO. 2  
PREVENT ARTHRITIS  
WHENEVER POSSIBLE**

**OBJECTIVE NO. 1**

*Support goals and objectives in the Oregon Physical Activity and Nutrition Plans.*

**Strategies:**

1. Collaborate with statewide physical activity and nutrition programs to expand the availability of arthritis-related prevention messages.
2. Identify key strategies in the Oregon Physical Activity and Nutrition Plans and collaborate with physical activity and nutrition programs to address mutual goals.

**OBJECTIVE NO. 2**

*Increase the number of partnerships with chronic disease programs and other organizations in order to leverage educational, public policy, outreach and funding opportunities.*

**Strategies:**

1. Contact and recruit interested organizations to network and build a strong statewide Arthritis Coalition.
2. Identify ways to connect and work with other chronic disease prevention programs at the state and federal level.

**OBJECTIVE NO. 3**

*Identify at-risk groups and determine appropriate interventions.*

**Strategies:**

1. Recognize and prioritize specific population groups that are at an increased risk for arthritis.
2. Create new programs, or tailor existing ones, to meet the needs of the identified groups (ensuring inclusion of exercise and biomechanics) and collaborate with community partners for implementation.

**GOAL No. 3**  
**INCREASE THE NUMBER OF SELF-MANAGEMENT EDUCATIONAL RESOURCES**

**OBJECTIVE No. 1**

*Increase the number of people who receive arthritis self-management educational resources.*

**Strategies:**

1. Identify where the Arthritis Foundation Exercise Program and Living Well with Chronic Conditions Programs already exist on a statewide basis and address the gaps and areas for improvement.
2. Encourage health care providers to make referrals to organizations that provide self-management resources.
3. Design and implement a media campaign to inform the public about the importance of self-management and the availability of classes, including multi-lingual resources.

**OBJECTIVE No. 2**

*Reduce the percentage of people with arthritis who experience a limitation in activity due to arthritis.*

**Strategies:**

1. Increase the number of senior nutrition sites that offer the Arthritis Foundation Exercise Program to improve the performance of daily activities.
2. Increase the availability of linguistically and culturally appropriate self-management programs and support groups.

**GOAL No. 4**  
**EXPAND THE AVAILABILITY OF EDUCATIONAL AND COMMUNITY-BASED RESOURCES**

**OBJECTIVE No. 1**

*Increase the number of people with arthritis who engage in overall daily physical activity.*

**Strategies:**

1. Develop new resources for physical activity opportunities tailored for people with arthritis.
2. Make linkages with community partners to expand arthritis programs and disseminate resource information.
3. Collaborate with partners to incorporate the “Physical Activity. The Arthritis Pain Reliever” campaign on an ongoing basis.

**OBJECTIVE No. 2**

*Support and partner with the Arthritis Foundation, Pacific Northwest Chapter in Oregon.*

**Strategies:**

1. Identify and establish mutual goals between the Arthritis Coalition and the Arthritis Foundation, Pacific Northwest Chapter.
2. Work in partnership with the Arthritis Foundation, Pacific Northwest Chapter to accomplish measurable outcomes for program activities.

**OBJECTIVE No. 3**

*Increase educational opportunities for health care providers and long-term care providers throughout Oregon.*

**Strategies:**

1. Evaluate and revise existing arthritis educational tools to facilitate low-cost trainings for health care and long-term care providers, health educators and individuals with arthritis; disseminate tools.
2. Evaluate and revise existing pain management modules for health care and long-term care providers, health educators and individuals with arthritis; disseminate tools.

**GOAL NO. 5  
MONITOR THE IMPACT  
OF ARTHRITIS**

**OBJECTIVE NO. 1**

*Monitor Oregon-specific arthritis data related to prevalence, activity limitations, use of health care services, costs of health care services, overall quality of life, and self-management.*

**Strategies:**

1. Continue to monitor Oregon-specific arthritis data related to prevalence, activity limitations, quality of life, self-management, and cost of health care services.
2. Continue evaluation of Oregon's Arthritis Foundation Exercise Program.

**OBJECTIVE NO. 2**

*Maintain and expand Oregon-specific data.*

**Strategies:**

1. Collaborate with coalition members and other organizations on the collection, formatting and dissemination of useful arthritis information.
2. Identify other sources of arthritis related data.

**OBJECTIVE NO. 3**

*Increase the dissemination of data and information collected.*

**Strategies:**

1. Combine data with compelling stories.
2. Present data to health care purchasers and providers demonstrating the potential long-term positive impact of providing appropriate interventions.

## FOCUS ON CHILDREN

*Kids get arthritis, too. According to the Arthritis Foundation, nearly 300,000 American children suffer from some form of Juvenile Rheumatoid Arthritis (JRA). Unfortunately, we do not have statistics on the number of children suffering from this disease in the state of Oregon.*

### MY PERSONAL STORY

*“I thought only old people got arthritis”... so did my family until I turned 5 years old and came face to face with a disease that would rob me of a normal carefree childhood. Now 23 years later, I realize that this stumbling block on the road of my life has been my stepping-stone to speak out and help others realize that arthritis affects young and old alike.*

*When I was diagnosed in 1982 the best medication available was the wonder drug... aspirin. It helped ease the pain and became my best friend three times a day. At 15 my arthritis went into remission. This was a great blessing but at that point after having juvenile rheumatoid arthritis (JRA) active in my body for 10 years it had done irreversible damage to many of my joints. I lost mobility in my knees, shoulders, ankles and elbows and surgery was a definite part of my future. I finished out high school with one knee surgery behind me and went off to college. At age 20 my arthritis came back—we knew this was a possibility. In a matter of six years, thanks to medical research, new medications were available. These new medications have the ability to relieve the debilitating symptoms enabling people with this disease to lead a more normal and active life.*

*In the beginning JRA defined my life and limitations but thanks to the support of family, doctors and many medical professionals*



*who donate their time and money to arthritis research I now define my life and what will limit me. Although I continue to deal with pain and frustration from JRA, with surgeries inevitable in my future, I know that with generous contributions, whether it is time, talent, financial or otherwise, together we can battle a disease that affects all ages.*

*—Jeanette Hill*

# Goal 1 INCREASE AWARENESS of ARTHRITIS

## OBJECTIVE NO. 1

*Increase public awareness of the cost, health impact, and prevalence of arthritis among children and adults.*

### Strategies:

1. Develop a media campaign that addresses the cost, health impact and prevalence among children and adults that can be adapted to various audiences.
2. Contact and recruit legislators, decision-makers, health systems, insurers, and private industry to recognize the need to fund programs that increase the availability of resources for people with arthritis.

## OBJECTIVE NO. 2

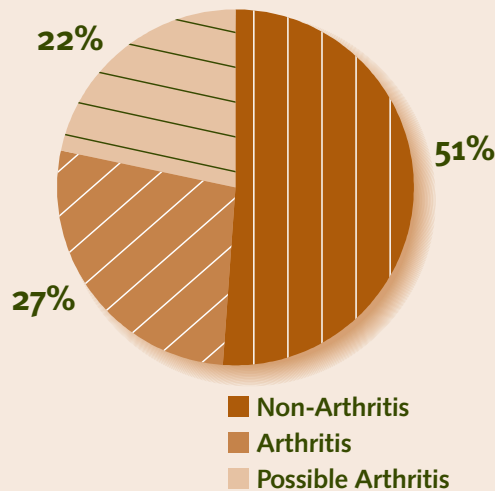
*Increase the awareness of arthritis services available throughout Oregon.*

### Strategies:

1. Develop a resource guide that can be made available to the public.
2. Collaborate with local healthcare and social service agencies to provide information about community resources for people with arthritis.

*Results from the 2004 Oregon Behavioral Risk Factor Surveillance Survey demonstrate that arthritis is a major public health issue in this state: the prevalence of clinically diagnosed arthritis among adult Oregonians is 27%. An additional 22% reported “possible arthritis” (chronic joint symptoms in the absence of diagnosis by a healthcare provider). It is estimated that 1,322,315 adults in Oregon have arthritis or chronic joint symptoms.*

Percentage of Adult Oregonians with Arthritis, 2004



*Data on children not available in Oregon*

## Goal 2 PREVENT ARTHRITIS WHENEVER POSSIBLE

Physical activity and good nutrition are key factors in reducing the impact of chronic diseases such as arthritis. Physical activity in itself helps decrease joint pain and improve mobility. In addition, lack of physical activity and excessive calorie intake lead to the development of overweight and obesity, which can cause osteoarthritis and exacerbate other kinds of arthritis. The Statewide Public Health Nutrition Plan and the Statewide Physical Activity Plan have at their core a focus on developing communities where healthy choices are the easy choices: where adults and children have easy access to quality, affordable fruits and vegetables; where Oregonians can safely walk and bicycle for work, errands and recreation. Both plans aim to eliminate health disparities among racial and ethnic communities, medically under-served, low-income, senior, disabled, and rural populations.

### OBJECTIVE NO. 1

*Support goals and objectives in the Oregon Physical Activity and Nutrition Plans.*

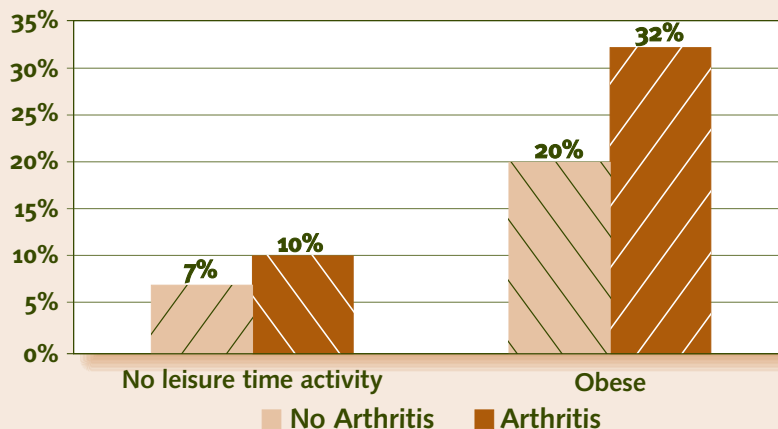
#### Strategies:

1. Collaborate with statewide physical activity and nutrition programs to expand the availability of arthritis-related prevention messages.
2. Identify key strategies in the Oregon Physical Activity and Nutrition Plans and collaborate with physical activity and nutrition programs to address mutual goals.

*continued on page 8*

*The 2004 Oregon Behavioral Risk Factor Surveillance Survey (BRFSS) suggests that people with arthritis are more likely to be physically inactive. The prevalence of no leisure time activity is 10% among those with arthritis, compared to 7% among those without arthritis. In addition, 32% of adults with arthritis are obese, whereas among adults without arthritis, only 20% are obese.*

**Obesity Status and Lack of Leisure Time Activity Among Adult Oregonians with and without Arthritis, 2004**



## FOCUS ON PREVENTION

### Modifiable Risk Factors for the Development and/or Progression of Arthritis

#### MAINTAIN A HEALTHY WEIGHT

For an overweight person, weight loss is a key modifiable risk factor to reduce strain on the knee and other weight-bearing joints, resulting in reduced symptoms and longer life span of the person's own joint or an artificial joint when that is required.

*Maintain optimal weight to reduce strain on normal or diseased/damaged joints. The strain placed on the knee joint is 3 times the weight being carried by the knee. If a person carries 20 pounds of weight in the form of excess body weight or a heavy object, the equivalent of 60 pounds is felt by the internal structures of the knee.*

A well-balanced diet that includes the daily-recommended servings of fruits, vegetables, and grains plus physical activity are important elements in achieving and maintaining a healthy weight.

Starting nutrition education at a young age and addressing poor eating habits as well as the content of vending machines in schools, colleges and the work place may be key targets in the attempt to modify the eating habits of Oregonians.



#### REGULAR PHYSICAL ACTIVITY

Regular aerobic and weight-bearing exercise is important to maintain strong muscles, which interestingly are more important shock absorbers than joint cartilage. Weight-bearing exercise is also important for bone health and reduces the risk of osteoporosis. The type and intensity of exercise should be adapted for people with arthritis and known joint damage.

The importance of regular physical activity and healthy eating needs to be supported on a local and statewide level.

#### PROTECTING YOUR JOINTS

##### Heavy Physical Labor

People involved in heavy physical labor should receive educational information about the importance of joint health. Certain occupations (i.e.,

*About 48% of those with clinically diagnosed arthritis report limiting their usual activities because of the condition, while 40% report that their work productivity is decreased by arthritis. Based on the 2004 Oregon BRFSS, 27% of adult Oregonians (about 695,000 people) suffer from arthritis.*

shipyard work, farming, heavy industry, and occupations with repetitive motion, etc.) are associated with an increased risk of arthritis.<sup>2</sup> Similar to athletes, manual laborers must be allowed to acclimate their bodies to the physical strain of their job. Employers providing equipment, such as back-braces and kneepads, lessens the chance of injury. Addressing ergonomics at the work place can reduce strain on workers' joints and muscles. When workers are injured, receiving adequate medical care and rehabilitation is important, so that they can return to their place of work.

##### Sports Injury

People participating in sports need to be aware of the long-term consequences of trauma to joints and overall well being. Coaches and athletes can follow training programs aimed at progressive conditioning and setting realistic goals to prevent over-use injuries. Use of protective gear and adequate officiating at competitions may result in reduced trauma. Adequate first aid and sport medicine/orthopedic interventions are best practices to follow in the case of trauma. Following an injury, adjustments to training programs and competition are vital during the rehabilitation phase.

Long after the impact and the immediate treatment of a sports injury, however, problems may appear. Adolescents and young adults with traumatic injury are at substantially increased risk for osteoarthritis at the same joint later in life.<sup>3</sup>

*Education about the multiple benefits of exercise and reducing strain on one's joints needs to be strongly encouraged at all stages of life, starting at a young age throughout formal education and at the work-place.*

Building healthy bones begins at birth and lasts your whole life.



# Goal 2 PREVENT ARTHRITIS WHENEVER POSSIBLE *continued from p. 6*

## OBJECTIVE NO. 2

*Increase the number of partnerships with other chronic disease programs and other organizations in order to leverage educational, public policy, outreach and funding opportunities.*

### Strategies:

1. Contact and recruit interested organizations to network and build a strong statewide Arthritis Coalition.
2. Identify ways to connect and work with other chronic disease prevention programs at the state and federal level.

## OBJECTIVE NO. 3

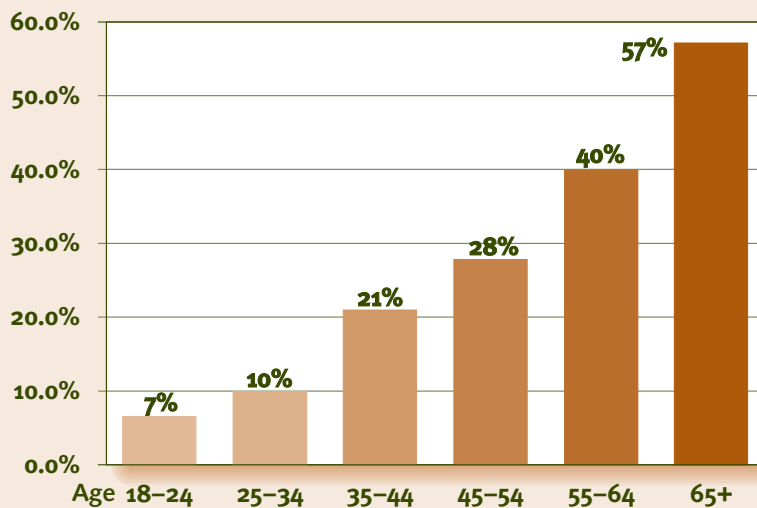
*Identify at-risk groups and determine appropriate interventions.*

### Strategies:

1. Recognize and prioritize specific population groups that are at increased risk for arthritis.
2. Create new programs, or tailor existing ones, to meet the needs of the identified groups (ensuring inclusion of exercise and biomechanics) and collaborate with community partners for implementation.

*Older Oregonians are more commonly affected by arthritis. The prevalence of arthritis increases with age. This is not to say that the elderly are the only ones affected by arthritis. Nearly 65% of Oregonians with clinically diagnosed arthritis are under 65 years old.*

**Percentage of Adult Oregonians in Various Age Groups Who Report Having Clinically Diagnosed Arthritis, 2004**





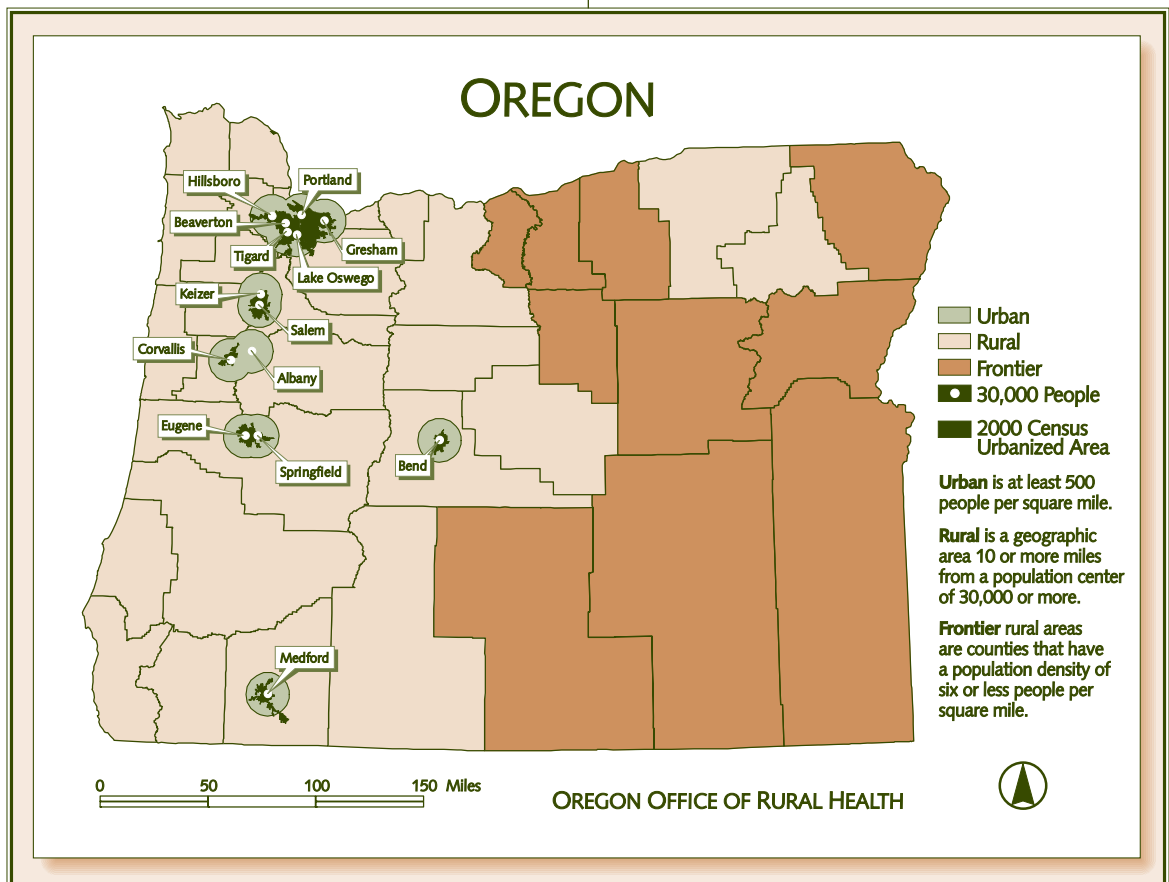
## FOCUS ON WHO'S AT RISK



*Andy has arthritis, but keeps his joints moving by sawing up firewood to burn in his stove during the winter months.*

### Rural Communities

Much of Oregon is rural. People with arthritis in rural communities are at a greater risk for not getting their health care needs met. In rural areas, it is common to serve a higher proportion of patients who are either on Medicare, Medicaid, or do not have any insurance.<sup>4</sup> It is common for people to drive themselves, family or friends to primary and specialty clinics that are long distances from where they live. Other means of transportation are not an option for most of these communities. There are also fewer educational resources available that people are able to access.



### **Oregon's Aging Population**

*The number of Oregonians over the age of 65 is expected to double in the next two decades. Arthritis will have a growing impact on the health, mobility, and quality of life of its older population.*

*While Oregon is ahead of many states in providing a range of community-based services to help frail older adults, many challenges still face older individuals with arthritis. These challenges include access to healthcare, especially in rural communities; transportation to healthcare, exercise programs, and support services; dealing with additional health conditions; and isolation for those living alone. Older adults are less active than the general population (Oregon BRFSS 2004 data). Information, programs, and support for exercise programs designed for frail older adults with arthritis are not available or accessible in much of the state. As mobility decreases, older adults face the need for increased support through home modifications, in-home care, or moving into community-based care settings. Identifying ways to reach and support the increasing number of older adults with arthritis will be a challenge to health and long-term care systems, policymakers, local health and aging agencies, and caregivers.*

—Jennifer Mead, MPH, Health Promotion Coordinator, DHS Seniors & People with Disabilities

### **Racial and Ethnic Communities**

A large body of literature has documented significant racial and ethnic disparities in health care and health outcomes, with minority Americans generally receiving less health care and suffering worse health.<sup>5</sup> The disabling affects of arthritis (e.g. arthritis-attributable activity limitations, work limitations, and severe joint pain) affect racial/ethnic minorities disproportionately.<sup>6</sup>

Financial, structural, and personal barriers can limit access to health care for racial and ethnic minorities.

- Financial barriers include not having health insurance, not having health insurance to cover needed services, or not having the financial capacity to cover services outside a health plan or insurance program.
- Structural barriers include the lack of primary care providers, medical specialists, or other health care professionals to meet special needs or the lack of health care facilities.
- Personal barriers include cultural or spiritual differences, language barriers, not knowing what to do or when to seek care, or concerns about confidentiality or discrimination.<sup>7</sup>

### **People with Disabilities**

Arthritis is the most common reported cause of disability, and the third leading cause of work limitation in the United States.<sup>8</sup>

People with disabilities, either caused or exacerbated by arthritis, face the added barriers of access to appropriate treatment and exercise programs, transportation and employment, and may find it more difficult to live independently.

### **Children**

Limited services for children with arthritis make it necessary for many families to drive long distances to access limited resources. There are few pediatric rheumatologists in Oregon, and many children who could benefit from evaluation by these specialists may not have the opportunity.

Schools need to be aware of the physical limitations and difficulties that students with inflammatory arthritis may experience, and through simple accommodations can significantly improve a child's school experience.



*At 93, Margaret keeps active so she can prune her trees once a year.*

# Goal 3 INCREASE THE NUMBER of SELF-MANAGEMENT EDUCATIONAL RESOURCES

## OBJECTIVE NO. 1

*Increase the number of people who receive arthritis self-management educational resources.*

### Strategies:

1. Identify where the Arthritis Foundation Exercise Program and Living Well with Chronic Conditions program already exist on a statewide basis and address the gaps and areas for improvement.
2. Encourage health care providers to make referrals to organizations that provide self-management resources.
3. Design and implement a media campaign to inform the public about the importance of self-management and the availability of classes, including multi-lingual resources.

### Arthritis Foundation Exercise and Aquatic Programs

Our bodies were designed to move, so daily physical activity is important for all of us.

The Arthritis Foundation Exercise Program and Aquatics Program are for people with arthritis. These “easy on the joints” workouts help in maintaining or improving range of motion, flexibility, strength and endurance. Instructors must be certified by the Arthritis Foundation to teach these classes.



### Self-Management Programs

Self-management resources are programs that have been evaluated and proven to improve the health status of people with arthritis. Some existing classes that are currently available in Oregon include: Arthritis Foundation Exercise Program, Arthritis Foundation Aquatic Program, and Living Well with Chronic Conditions. The goal is to have more programs in Oregon by finding out where the need is, creating awareness in those communities and linking programs together for easier accessibility.

*As an instructor for both the land and water programs, I see and hear the ways in which an appropriate exercise program has improved lives of class participants. For some, it's standing taller and walking more easily, sometimes with a “bounce” in their step or the smile that lets you know they feel better. One participant bragged she could now walk the entire length of her long driveway to pick up her own mail and newspaper. Comments such as “my joints are working better and I’m ready to face my day,” or “I came because my doctor told me to. I’m coming back because I had fun” lets instructors*

*know the value of the Arthritis Foundation Exercise Program.*

*I enjoy the challenges of teaching and feel privileged to “work out” with people some of whom, because of their physical limitations, expend, each day, as much energy on daily activities as does a marathon runner during a race.*

— Carol Clark

*Master Trainer and Instructor of the Arthritis Foundation Aquatic & Exercise Program*

*continued on p. 13*

## FOCUS ON SELF-MANAGEMENT PROGRAMS

### Living Well with Chronic Conditions

Living Well with Chronic Conditions (CDSMP—Chronic Disease Self-Management Program) was developed at the Stanford University Patient Education Research Center as a collaborative research project between Stanford and the Northern California Kaiser Permanente Medical Care Program.

In a five-year research project, the program was evaluated in a randomized study involving more than 1000 subjects. This study found that people who took the program, when compared to people who did not take the program, improved their healthful behaviors (exercise, coping, communications with physicians, and cognitive

symptom management), improved their health status (self-reported health, fatigue, disability, social role/activities limitations, and health distress), and decreased their days in the hospital.

Oregon Department of Human Services is supporting statewide dissemination of the program through trainings at the master and leader level.

It is the process through which the Living Well with Chronic Conditions is taught that makes it effective. Sessions are highly participatory. Mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives.

### LIVING WELL WITH CHRONIC CONDITIONS

#### OVERVIEW OF TOPICS

	WEEKS					
	1	2	3	4	5	6
Overview of self-management & chronic health conditions	●					
Making an action plan	●	●	●	●	●	●
Relaxation & symptom management	●		●	●	●	●
Feedback & problem-solving		●	●	●	●	●
Managing anger, fear, & frustration		●				
Fitness & exercise			●	●		
Better breathing			●			
Fatigue			●			
Nutrition				●		
Advance directives				●		
Communication				●		
Medications						●
Making treatment decisions						●
Depression						●
Informing your healthcare team						●
Working with your healthcare professional						●
Future plans						●

*"The Chronic Disease Self-Management Workshop Leaders Manual,"  
Stanford Educational Research Center, [www.patienteducation.stanford.edu](http://www.patienteducation.stanford.edu)*

# Goal 3 INCREASE THE NUMBER of SELF-MANAGEMENT EDUCATIONAL RESOURCES *continued from p. 11*

## OBJECTIVE NO. 2

*Reduce the percentage of people with arthritis who experience a limitation in activity due to arthritis.*

### Strategies:

1. Increase the number of senior nutrition sites that offer the Arthritis Foundation Exercise program to improve the performance of daily activities.
2. Increase the availability of linguistically and culturally appropriate self-management programs and support groups.

### Impact of Arthritis

Arthritis can have an enormous impact on a person by restricting their daily activities, affecting their ability to work and decreasing the quality of life for millions of Americans.<sup>9</sup>

More than 8 million Americans report that arthritis circumscribes things that people do everyday, such as walking and dressing.<sup>10</sup>

The physical limitations are only part of the larger picture. Along with physical changes, a person is challenged by fatigue, depression and pain. Just the emotional ups and downs that are associated with the loss of physical function can affect the level of pain and fatigue a person lives with on a daily basis. Arthritis pain can be one of the most difficult and exhausting symptoms to manage on a daily basis. Pain management is fundamental for a person to improve their quality of life.

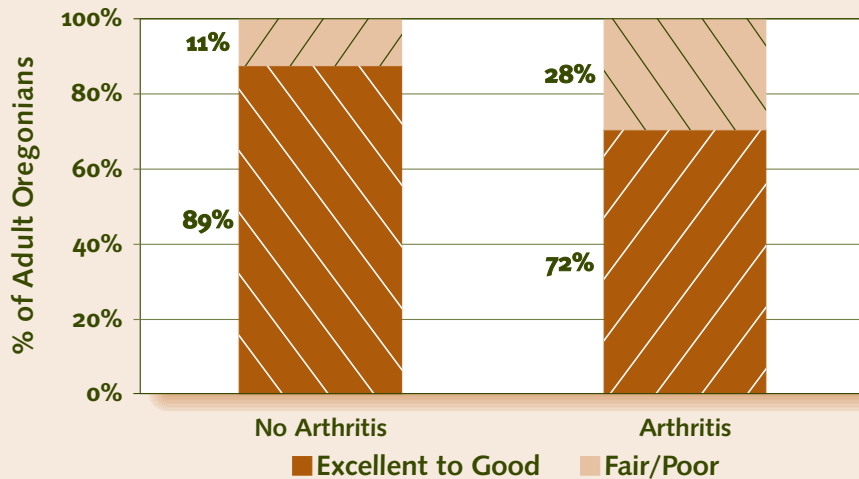
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**30%** of adult Oregonians with arthritis also have depression (depression call-back survey, 2004-2005).

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*Those living with arthritis report decreased quality of life. Oregonians with arthritis are also more likely to report poorer health status (28%) compared to those without arthritis (11%).*

**Health Status Among Oregonians with and without Arthritis, 2004**



## FOCUS ON EXERCISE

### NO PAIN, NO PAIN APPROACH TO MOVE BEYOND PAIN!



*During my recovery from fibromyalgia, I kept hearing that when you begin exercising, it gets worse before it gets better and the “no pain no gain” mindset made things even worse. So when it came to movement, I instead adopted the “No Pain, No Pain” mantra. It means that if there is no pain and discomfort while doing the movements then there is no more pain later on.*

*As a clinical exercise physiologist, researcher, therapist and a person with chronic pain, I would like to encourage people to be as active as they can be by using and not abusing their body. Remember, exercise is as important for a person with chronic pain as insulin is for a person with diabetes. It is their lifeline.*

*—Namita Gandhi  
Clinical Exercise Physiologist  
Integrative Movement Clinic*



*Betty gets to work on strengthening her upper arms while trying to keep the beach ball on the parachute. Senior centers around Oregon have Arthritis Foundation Exercise Programs so that seniors can stay active and keep independent.*



*Exercise is not the only reason to be in the pool at Matt Dishman Community Center. Laughing, socializing and just having fun is why people take a water aerobics class.*

# Goal 4 EXPAND THE AVAILABILITY of EDUCATIONAL & COMMUNITY-BASED RESOURCES

## OBJECTIVE NO. 1

**Increase the number of people with arthritis who engage in overall daily physical activity.**

### Strategies:

1. Develop new resources for physical activity opportunities that are tailored for people with arthritis.
2. Make linkages with community partners to expand arthritis exercise programs and disseminate resource information.
3. Collaborate with partners to incorporate the “Physical Activity. The Arthritis Pain Reliever” campaign on an ongoing basis.

### Expanding Exercise Programs

*I have been teaching a class for the past 7 years. This class is comprised of women between the ages of 68-90 yrs of age. The class mainly consists of the Arthritis Foundation flexibility and strengthening exercises. I also add a balance component. It does not contain an aerobic component so I encourage participants to add a daily walk.*

*The seniors I teach are a joy to work with. They are loyal to the class and to each other. Feedback I receive from them is that the social interaction and motivation from the group is what keeps them exercising on a regular basis. They tell me they would not exercise if they were at home alone.*

*They also tell me that they feel safe and don't worry about injury when they exercise in class. This comfort level encourages them to extend themselves a little more and try new exercises from time to time.*

*The benefits of exercise for all of them are to enjoy each other, feel better, stronger, and more flexible. Each of them expresses that exercise increases their confidence level so that they are able to live their lives as fully as possible. As an occupational therapist, I feel that increasing independence and quality of living are the main goals for exercise, so I am pleased that the participants express that this is what is happening for them.*

—Lauren Rykert, OTR/L  
OASIS HealthStages Coordinator

*Lauren keeps her class smiling as they move through their exercises.*



# Goal 4 EXPAND THE AVAILABILITY of EDUCATIONAL & COMMUNITY-BASED RESOURCES *continued*

## OBJECTIVE NO. 2

**Support and partner with the Arthritis Foundation, Pacific Northwest Chapter in Oregon.**

### Strategies:

1. Identify and establish mutual goals between the Arthritis Coalition and the Arthritis Foundation, Pacific Northwest Chapter.
2. Work in partnership with the Arthritis Foundation, Pacific Northwest Chapter to accomplish measurable outcomes for program activities.

### Arthritis Foundation Support

*Working with the Arthritis Foundation volunteers in Oregon over the past several months to provide leader trainings for the Arthritis Foundation Exercise and Aquatics Programs has been a wonderful experience. Whether it's exercise program trainers demonstrating how to effectively lead classes, future class instructors, or host facility staff, the combination of enthusiasm, knowledge, and dedication in these volunteers is phenomenal and bodes well for the future of arthritis interventions in Oregon as well as the future of the Arthritis Foundation.*

—Johanna Lindsay, Director of Programs and Services, Arthritis Foundation, Pacific Northwest Chapter

*We are most grateful for the strong support and partnership we have with the Oregon Arthritis Program. We commend the state of Oregon for providing such a very effective outreach program for Oregonians with arthritis!*

—Marilee McCorriston, President/CEO, Arthritis Foundation, Pacific Northwest Chapter

*The Arthritis Foundation is committed to having a strong presence to serve Oregonians who have arthritis. Throughout the nation, we are focusing on juvenile arthritis, rheumatoid arthritis, and osteoarthritis in the areas of research, public health and public policy. We will continue to expand our exercise and self-management programs to improve the quality of life for people with arthritis and their families in Oregon. Our advocacy efforts will focus on seeking expanded government support of research and encourage Congress to expand its funding of the Center for Disease Control arthritis*

*programs so that the Oregon State Health Department and other such departments nationally will implement activities to address the needs of people with arthritis. This will be enhanced by the formation of the Arthritis Foundation, Pacific Northwest Chapter to serve Oregon, Washington and Alaska. The Arthritis Foundation commends the Oregon Arthritis Coalition in its efforts to reduce the pain and disability associated with arthritis and pledges its support of these efforts in Oregon. With the help and generosity of the people of Oregon, we will lead the effort to raise the necessary funds to make our programs accessible throughout Oregon and to fund research seeking better treatments and the cure for arthritis.*

—Judy McAbee, Chief Organizational Development Officer, Arthritis Foundation, National Office

### Arthritis Foundation Helps Children Live “Normal” Lives

*A major concern of many parents with children who have JRA—Juvenile Rheumatoid Arthritis—is how to help their children live a “normal” life. One of the goals of pediatric rheumatologists is to keep children active so that children can be children. However, as one parent of a preschooler with polyarticular JRA asks, “What do you say to a 4-year old who comes home from school, crying because she can't run as fast as the other kids?”*

*A parent of a 16-year old girl who suffers from systemic JRA explains, “Our goal is to keep her in school. She dances when she can, and she skis when she can. She fatigues easily. Homework can be a challenge after a long day at school. She has learned to live with the pain that has been daily for six years.”*

—Dawn Kimball, Juvenile Arthritis Task Force

### ELLIE'S STORY

**T**wo weeks before her second birthday, Ellie was diagnosed with polyarticular Juvenile Rheumatoid arthritis (JRA). To prevent long-term joint damage, Ellie started receiving weekly injections of a strong chemotherapy drug that would suppress her immune system from attacking her joints. Physical therapy helped Ellie gain endurance and learn to climb the stairs again. Since Ellie tested positive for a certain marker in the blood that increases her risk for uveitis, a chronic eye inflammation related to JRA, Ellie started seeing a pediatric ophthalmologist every three months.



### OBJECTIVE NO. 3

*Increase educational opportunities for health care providers and long-term care providers throughout Oregon.*

#### Strategies:

1. Evaluate and revise existing arthritis educational tools to facilitate low-cost trainings for health care and long-term care providers, health educators and individuals with arthritis; disseminate tools.
2. Evaluate and revise existing pain management modules for health care and long-term care providers, health educators and individuals with arthritis; disseminate tools.

#### Widening the Reach with Education

*Medical students, internal medicine residents and subspecialty residents such as those in dermatology, family practice, obstetrics and gynecology receive regular lectures in disease recognition and management from faculty members such as the Arthritis & Rheumatic Diseases Division at Oregon Health Sciences University. Physician assistants receive similar instruction and often practice in rural areas of Oregon with minimal*

After a year of no severe inflammation, Ellie's pediatric rheumatologist suggested that she might be in remission. For now, Ellie taps and swims and climbs rock walls—when just years ago, she couldn't climb the stairs in her house.



*access to specialized care. The Oregon Society of Physician Assistants frequently invites rheumatologists to provide updates on disease diagnosis and management at their continuing education meetings. This also builds a bridge between specialists and primary care providers practicing in remote locations. Teaching faculty lecture at hospital grand rounds and medical staff meetings across the state providing updates to health care providers around the metropolitan area of Portland. Other organizations that have an interest in continuing education about arthritis are nurse practitioners, naturopaths, massage therapists and chiropractors.*

*Regular meetings are held with major health insurance companies to ensure access to care and coverage for costly medications. Members of the Oregon Rheumatology Alliance are frequently called upon to lecture to local physicians, hospitals and health care purchasers in smaller communities such as Salem, Eugene, Medford, Bend and Hood River as well as in Portland.*

—Andre Barkhuizen, MD, FCP,  
Associate Professor of Medicine,  
Arthritis and Rheumatic Diseases,  
Oregon Health and Science University,  
Oregon Rheumatology Alliance Member

*Oregon Medical Professional Review Organization (OMPRO) has been working with Oregon nursing homes for the past three years as part of the national Nursing Home Quality Initiative. One of the key areas of focus has been improving pain management for residents, which is often under-detected and under-treated. An estimated 45% to 83% of nursing home residents are reported to be in pain at any one time.*

*Arthritis is a common condition that is the cause of pain among nursing home residents. We strongly support the objective of increasing educational opportunities for long term care providers to promote better recognition and appropriate management of pain in Oregon's elders.*

—Jennifer Martin, MPH, Nursing Home  
Quality Initiative—Team Lead, OMPRO

## FOCUS ON MANAGEMENT & TREATMENT



*Dr. Barkhuizen enjoys teaching residents about arthritis.*

### Management and Treatment

Arthritis can occur at any age and in all races. Early and correct diagnosis is the first and probably most important step in reducing long-term disability by making it possible to start appropriate therapy before irreversible damage has occurred.

### Ongoing Education

Although there is no single remedy to cure arthritis, there are different options to help manage many different types of arthritis. Research

shows that early diagnosis and appropriate management can help lessen the consequences associated with many types of arthritis.<sup>11</sup>

Early diagnosis requires adequate public education so that people with arthritis symptoms can seek help from health care providers. Organizations such as the Arthritis Foundation and various disease specific foundations and patient support groups are key partners in reaching the public to provide useful information about treatment and prevention of arthritis. The lay press and television media can reach individuals in remote areas of the state.

Health care providers need ongoing training to diagnose, treat and appropriately refer patients with arthritis. Correct diagnosis is important and adequate training is required to manage these disorders appropriately and safely.

### Self-Management

People with chronic diseases live with the condition on a daily basis; they are the “leader of their own team.”

Self-management programs teach people to take control of their arthritis by acquiring the skills, knowledge and attitudes to empower themselves to make better decisions that involve pain relief, problem solving, behavior changes with exercise and reducing stress in their lives.

**“Physical Activity. The Arthritis Pain Reliever”** is a campaign designed to promote physical activity as a method of arthritis self-management. Physical activity can have an important and beneficial effect on arthritis pain and associated disability.

The campaign promotion materials are designed to:

- Raise awareness of physical activity as a way to manage arthritis pain and increase function.
- Increase understanding of how to use physical activity (types and duration) to ease arthritis symptoms and prevent further disability.
- Enhance the confidence or belief of persons with arthritis that they can be physically active.
- Increase trial of physical activity behaviors.



Health care providers, long term care, health educators and social services need to be educated about local community resources that provide education and support for people with arthritis. These agencies can make referrals to programs locally and educate patients on the importance of self-management, exercise programs and educational resources that are found in their community.

### Occupational and Physical Therapy

*When people are diagnosed with arthritis, they are often referred to an occupational or a physical therapist. These professionals are experts in evaluating a person's movement and recommending changes to maximize function.*

*The therapist will assess the patient's strength, range of motion, coordination and endurance before developing a plan of care to address any deficits and to assist with the management of symptoms. In most cases, the therapist will provide the patient with strategies for protecting the inflamed joints. These strategies could include fabricating a splint, recommending a brace or an assistive device (like a walker or cane), or prescribing an exercise program that will develop the surrounding muscles to support the joint. Therapists are experts in providing "hands on" care to improve joint and soft tissue mobility. The most important goal of occupational or physical therapy, though, is to provide patients with the tools to begin to manage their disease independently and to serve as a bridge to other community resources.*

*—Robert Love, OTR/L, American Occupational Therapy Association & Chris Murphy, PT, Outpatient Rehabilitation, Providence*

### Medications

Medications commonly used to treat rheumatic diseases provide relief from pain and inflammation. Other medications can help reduce structural damage done to the joint.

The very effective yet costly injectable biological medications promise to greatly improve quality of life for inflammatory arthritis sufferers.

For example, early use of disease modifying anti-rheumatic drugs (DMARDs) for rheumatoid arthritis can improve long-term health outcomes.<sup>11</sup> DMARDs are intended to slow or prevent damage to the joints and thereby prevent disability and discomfort.



### Surgery

Joints are sophisticated structures that are designed to work precisely. Surgery may be necessary to drain excess fluid from swelling or to trim away a jagged piece of cartilage that is causing pain. In some cases, a procedure such as total joint replacement may be necessary to completely replace a joint in which cartilage and bone are damaged severely.<sup>12</sup> The goal of joint replacements is to improve mobility by relieving pain and restoring the function in the joint.

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*The most common reason for having a hip or knee replaced is osteoarthritis, according to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Osteoarthritis commonly affects people over 45, although younger men and women can get this disease and need a joint replacement.*

*In 2004, the cost for hip, knee and shoulder replacements due to rheumatoid and osteoarthritis in Oregon was \$144 million.*<sup>13</sup>

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# Goal 5 MONITOR THE IMPACT of ARTHRITIS

## OBJECTIVE NO. 1

*Monitor Oregon-specific arthritis data related to prevalence, activity limitations, use of health care services, costs of health care services, overall quality of life, and self-management.*

### Strategies:

1. Continue to monitor Oregon-specific arthritis data related to prevalence, activity limitations, quality of life, self-management, and cost of health care services.
2. Continue evaluation of Oregon's Arthritis Foundation Exercise Program.

## OBJECTIVE NO. 2

*Maintain and expand Oregon-specific data.*

### Strategies:

1. Collaborate with coalition members and other organizations on the collection, formatting and dissemination of useful arthritis information.
2. Identify other sources of arthritis related data.

## OBJECTIVE NO. 3

*Increase the dissemination of data and information collected.*

### Strategies:

1. Combine data with compelling stories.
2. Present data to healthcare purchasers and providers demonstrating the potential long-term positive impact of providing appropriate interventions.

### Data

Data provides an eloquent language that we can use to describe the impact of arthritis among Oregonians. Through data, we can share the scope of this impact with policy-makers, we can determine whether treatments are effective in controlling disease, and we can learn what strategies might be most beneficial in our efforts to lessen the burden of arthritis in Oregon.

### EACH YEAR, ARTHRITIS IN THE UNITED STATES CONTRIBUTES TO:

- 9,500 deaths
- 750,000 hospitalizations
- 16 million people with limitations
- 36 million ambulatory care visits
- 43 million people with self-reported, doctor-diagnosed arthritis
- \$51 billion in medical costs and \$86 billion in total costs<sup>14</sup>

## FOCUS ON PROGRESS

### **CANDACE MUELLER**

I was a very happy commercial artist who swam a mile, did half-an-hour of yoga and an hour of meditation every morning. Arthritis forced me to reinvent myself. Self-pity isn't really my cup of tea, so I simply found the next "open door," and my husband and I started a small electronics manufacturing business.

### **JAN COCHRAN**

I have always lived by this motto—"The choices you make dictate the life you lead."

Being diagnosed with rheumatoid arthritis wasn't my choice, but the choosing how to live with RA has definitely dictated my life. Having a half full basket instead of a half-empty one is first on my list. The field of arthritis has come a long way, hope is on the horizon.

### **MARCI EDWARDS**

I am a 48-year-old special education teacher who continues to work even though typing is difficult, so I now use voice-activated software. I am currently taking three medications to control my arthritis, and this year I had surgeries on my right and left hands.

### **LIONEL KRONER**

I developed pain in my hands and wrists then a body flare, while at a camp for children with cancer in the 1980's. I have remained in remission due to medications since 1996. I am a very social person living in a retirement community and continue my volunteer activities with young people.



*Left to right: Candace, Jan, Marci, Lionel*

### **MUSCULOSKELETAL PATIENT EDUCATORS PROGRAM**

We partner with the supervising doctors to teach a musculoskeletal exam to second year medical students, pharmacy students, physician assistants, nurse practitioners, resident and doctors in practice. We use our joints in the exam to show what arthritis truly looks like by teaching students and providers how to inspect, palpate and measure range of motion and function of every joint. We also teach students and providers about the impact of arthritis on our activities of daily living and use of assistive devices to open a door, turning a key, opening jars and many other tasks to maintain independence while living with a chronic condition.

## HOW CAN YOU GET INVOLVED?

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*If you would like to get involved in the Arthritis Coalition and the efforts being made to reduce the growing burden of arthritis among Oregonians of all ages and communities, or would like additional copies of this report, contact the Oregon Arthritis Coalition at 971-673-0984, or via the web at [www.oregonhealth.org/arthritis](http://www.oregonhealth.org/arthritis).*

*There are opportunities for involvement working on statewide arthritis activities throughout Oregon.*

*There is room for everyone to participate.*

*Please join us!*

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*ALL THOSE who were willing to contribute their photos to the plan.*

*All Scenic photographs by Gary Halvorson, Senior Archivist, Oregon State Archives except Portland Skyline; Portland Oregon Visitors Association*

*Thanks to The Psoriasis Foundation for coordinating the printing of the Plan.*

## LOCAL & NATIONAL RESOURCES

### LOCAL RESOURCES

#### ARTHRITIS FOUNDATION, PACIFIC NORTHWEST CHAPTER

*The mission of the Arthritis Foundation is to improve lives through the prevention, control and cure of arthritis and related diseases.*

3876 Bridge Way N., No. 300  
Seattle, WA 98103  
Phone: 206-547-2707, 1-800-542-0295  
Email: info.wa@arthritis.org

#### THE NATIONAL PSORIASIS FOUNDATION

*Our mission is to improve the quality of life of people who have psoriasis and psoriatic arthritis.*

6600 SW 92nd Avenue, Suite 300  
Portland, OR 97223  
Phone: 503-244-7404, 1-800-723-9166  
Website: www.psoriasis.org

#### SCLERODERMA FOUNDATION

*To help patients and their families cope with scleroderma through supportive programs, promote public awareness and education, and support research to improve treatment and find the cause and cure of scleroderma.*

Oregon Chapter  
P.O. Box 19296  
Portland, OR 97280  
Phone: 503-245-4588  
Email: SDForegon@comcast.net

#### THE OREGON RHEUMATOLOGY ALLIANCE (ORA)

*ORA is a statewide non-profit advocacy group of rheumatology specialists dedicated to patient care and education. ORA members include nearly all the rheumatologists in Oregon and some rheumatologists in southern Washington as well. ORA provides advocacy, education and quality healthcare for all patients with rheumatic disease.*

Phone: 541-344-4162  
Email: ora@efn.org  
Website: www.oraonline.org/

### JUVENILE ARTHRITIS TASK FORCE

*In the Portland Metro area, a group of parents with children who suffer from JRA created the Oregon Juvenile Arthritis Task Force.*

Phone: 503-245-0684  
Email: orjasupport@comcast.net

### NATIONAL RESOURCES

#### NATIONAL ARTHRITIS FOUNDATION

*The Arthritis Foundation is the only national not-for-profit organization that supports the more than 100 types of arthritis and related conditions with advocacy, programs, services and research.*

P.O. Box 7669  
Atlanta, GA 30357-0669  
Phone: 1-800-823-7800  
Website: www.arthritis.org

#### NATIONAL FIBROMYALGIA ASSOCIATION

*To develop and execute programs dedicated to improving the quality of life for people with fibromyalgia by increasing the awareness of the public, media, government and medical communities.*

2200 N. Glassell St., Suite A  
Orange, Ca 92865  
Phone: 714-921-0150, Fax: 714-921-6920  
Website: www.fmaware.org/

#### THE LUPUS FOUNDATION OF AMERICA

*Our mission is to improve the diagnosis and treatment of lupus, support individuals and families affected by the disease, increase awareness of lupus among health professionals and the public, and find the causes and cure.*

2000 L Street, NW Suite 710  
Washington, DC 20036  
Office: 202-349-1155  
Health Educator: 202-349-1159  
To request a brochure about lupus:  
1-800-558-0121  
Website: www.lupus.org/



#### NATIONAL OSTEOPOROSIS FOUNDATION

*To prevent osteoporosis, to promote lifelong bone health, to help improve the lives of those affected by osteoporosis and related fractures, and to find a cure.*

1232 22<sup>nd</sup> Street NW  
Washington, D.C. 20037-1292  
Phone: 202-223-2226  
Website: [www.nof.org](http://www.nof.org)

#### SJOGREN'S SYNDROME FOUNDATION

*Our mission is to educate patients and their families, increase public and professional awareness, and encourage research into new treatments and a cure for sjogren's syndrome.*

8120 Woodmont Avenue, Suite 530  
Bethesda, MD 20814  
Phone: 301-718-0300  
Website: [www.sjogrens.org](http://www.sjogrens.org)

#### SPONDYLITIS ASSOCIATION OF AMERICA

*Our mission is to be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest.*

PO Box 5872  
Sherman Oaks, CA 91413  
Phone: 1-800-777-8189, 1-818-981-1616  
Email: [info@spondylitis.org](mailto:info@spondylitis.org)  
Website: [www.sponylitis.org](http://www.sponylitis.org)

#### NATIONAL INSTITUTE OF ARTHRITIS & MUSCULOSKELETAL & SKIN DISEASES

*Our mission is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases.*

1 AMS Circle  
Bethesda, Maryland 20892-3675  
Phone: 301-495-4484, 1-877-22-NIAMS  
(toll free), TTY: 301-565-2966,  
Fax: 301-718-6366  
Email: [niamsinfo@mail.nih.gov](mailto:niamsinfo@mail.nih.gov)  
Website: [www.niams.nih.gov/](http://www.niams.nih.gov/)

#### AMERICAN PAIN FOUNDATION

*Our mission is to improve the quality of life of people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.*

210 North Charles Street, Suite 710  
Baltimore, Maryland 21201-4111  
Website: [www.painfoundation.org](http://www.painfoundation.org)

#### AMERICAN COLLEGE OF RHEUMATOLOGY

*ACR works to better inform the medical community, the legislature and the public about the importance of Rheumatology and the impact of Rheumatic Disease.*

1800 Century Place, Suite 250  
Atlanta, GA 30345  
Phone: 404-633-3777  
Website: [www.rheumatology.org](http://www.rheumatology.org)

## ARTHRITIS DEFINITIONS

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*There are over 100 different types of arthritis. The following list includes some of the most common types and terms.*

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**Ankylosing Spondylitis** is a chronic, or long-lasting disease, that primarily affects the spine and may lead to stiffness of the back. The joints and ligaments that normally permit the back to move become inflamed. The joints and bones may grow (fuse) together. Some patients may also have inflammation of hips or shoulders affecting ability to walk or use their arms.

**Fibromyalgia** is a chronic syndrome that causes widespread pain in muscles and joints. Pain and localized tender points occur in the muscles and tendons, particularly those of the neck, spine, shoulders, and hips. Patients may also experience fatigue, memory problems, depression and sleep disturbances.

**Gout** is a form of arthritis that causes sudden, severe episodes of pain, tenderness, redness, warmth and swelling of joints. This type of arthritis results from deposits of needle-like crystals of uric acid in the connective tissue, joint space, or both. Uric acid is a normal breakdown product of purines, which are present in body tissue and in many foods. Usually, uric acid passes through the kidney into urine and is eliminated.

**Juvenile rheumatoid arthritis (JRA)** is the most common form of arthritis in children and is referred to as an autoimmune disease. Symptoms of JRA include fatigue, joint stiffness following sleep or inactivity, and weakness in muscles and other soft tissues. There is no single test to diagnose JRA. The diagnosis is determined by the presence of active arthritis in one or more joints for at least six weeks after other conditions have been ruled out.

**Lupus** is a disease of the immune system, which affects joints, skin, kidneys and other parts of the body. The immune system is your body's natural defense against infections, such

as bacteria and viruses. In lupus, the immune system produces antibodies that react with the body's own tissues. Because of this, lupus is referred to as an autoimmune disease. In most cases the term "lupus" refers to the form known as systemic lupus erythematosus.

**Osteoarthritis**, or "degenerative joint disease," most often affects the knees, hips, lower back and neck, small joints of the fingers and the base of the thumb and big toe. Degeneration of joint cartilage and changes in underlying bone and supporting tissues lead to pain, stiffness, difficulty with movement and activity.

**Osteoporosis** is a disease that causes bones to weaken and have an increased risk for fracture. This can lead to rounded shoulders, loss of height and even painful fractures (broken bones). The word osteoporosis means bone (osteo) that is porous or filled with holes (porosis).

**Pseudogout** is caused by the collection of calcium pyrophosphate crystals in joints. There may be attacks of joint swelling and pain in the knees, wrists, ankles, and other joints.

**Psoriatic arthritis** is a condition that causes pain and swelling in and around joints. It can show up in fingers and toes as well as the neck, lower back, knees, ankles, and other joints. Psoriatic arthritis is related to psoriasis, a lifelong skin disease that causes dry, scaly patches of skin.

**Rheumatoid arthritis** is referred to as an autoimmune disease and is characterized by chronic inflammation of the joint lining. Symptoms include pain, stiffness, and swelling of multiple joints. The inflammation may extend to other joint tissues and cause bone and cartilage erosion, joint deformities, movement problems, and activity limitation. Rheumatoid arthritis can also affect connective tissue and blood vessels throughout the body, triggering inflammation in a variety of organs, including the lungs and heart, and increasing a person's risk of dying of respiratory and infectious diseases.

**Scleroderma**—also known as systemic sclerosis, Scleroderma means “hard skin.” This disease could affect many parts of the body, such as the skin, blood vessels, digestive system (esophagus, stomach and bowel), heart, lungs, kidneys, muscles and joints. The exact cause of scleroderma is unknown. Evidence supports the notion that Scleroderma is an autoimmune disease because abnormalities of the immune system, particularly antinuclear antibodies (ANAs), are found in most people with scleroderma.

**Septic arthritis** develops when bacteria spread from a source of infection through the bloodstream to a joint or the joint is directly infected by traumatic penetration or surgical procedures. The onset of the symptoms is usually rapid with joint swelling, intense joint pain, and low-grade fever. Urgent treatment is required to prevent local damage to joints or spread of infection throughout the body.

## REFERENCES

1. Oregon's Arthritis Burden Report 2003
2. CDC. Prevalence of arthritis—United States, 1997. *MMWR* 2001;50:334–6.
3. Allan C. Gelber, MD, MPH, PhD; Marc C. Hochberg, MD, MPH; Lucy A. Mead, ScM; Nae-Yuh Wang, MS, PhD; Fredrick M. Wigley, MD; and Michael J. Klag, MD, MPH “Joint Injury in Young Adults and Risk for Subsequent Knee and Hip Osteoarthritis” *Annals of Internal Medicine* 2000; 133(5) Sept. 5: 321–328
4. Oregon Health & Science University, Office of Rural Health. (cited on 2005 August 4) Available from: <http://www.ohus.edu/oregonruralhealth/centerforruralhealth.html>
5. Minority Health, Cultural Competency of Health Care Providers could Reduce Disparities in Care Related to Race/Ethnicity. AHRQ, United States Department of Health and Human Services November 2000. (cited on 2005 August 11) Available from: <http://www.ahrq.gov/research/nov00/1100RA13.htm>
6. CDC. Racial/Ethnic Differences in the Prevalence and Impact of Doctor-Diagnosed Arthritis—United States, 2002. *MMWR* 2005;54(05) 119–123
7. Leading Health Indicators, Healthy People 2010. (cited on 2005 August 11).
8. CDC. Arthritis Prevalence and Activity Limitations—United States, 1990. *MMWR* 1994;34:433.
9. CDC. Prevalence of Disabilities and Associated Health Conditions among Adults—United States, 1999. *MMWR* 2001;50:120–5
10. Pope AM, Tarlow AR, eds. *Disability in America: toward a national agenda for prevention*. Washington. National Academy Press, 1991
11. Arthritis Foundation, ASTHO, Center for Disease Control and Prevention, 1999. *National Arthritis Action Plan*. Atlanta, GA.
12. *All You Need to Know About Joint Surgery*, Arthritis Foundation. Zimmer 2002.
13. 2004 Hospital Discharge Index provided by Oregon Association of Hospitals and Health Systems; Lake Oswego, OR.
14. CDC. *Targeting Arthritis: Reducing Disability for 43 million Americans*. (cited on 2005 December 1) <http://www.cdc.gov/nccdphp/publications/aag/arthritis.htm>



# QUESTIONNAIRE

## WHAT DO YOU THINK OF OREGON'S ARTHRITIS ACTION PLAN?

Please take a moment to give us your feedback regarding this publication. Results will help in developing and distributing future plans. Please detach and fold this survey and return by mail or fax to 971-673-0994.

Where did you obtain your report?  Mail  Internet  \_\_\_\_\_

Did you find this report to be useful?  Yes  No

If "YES," what did you find particularly useful? \_\_\_\_\_

If "NO," what would have made this report useful? \_\_\_\_\_

Was the content of this plan understandable?  Yes  No

If "NO," what suggestions do you have to make it more understandable? \_\_\_\_\_

What additional information would you have liked included? \_\_\_\_\_

What do you think of the Goals, Objectives and Strategies of this plan? \_\_\_\_\_

Are you interested in receiving information about Oregon's Arthritis Coalition?

Yes, send me some information.

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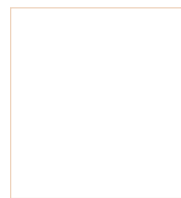
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## ARTHRITIS FROM A TO Z

**A**chilles tendinitis, Achondroplasia, Acromegalic athropathy, Adhesive capsulitis, Adult onset Still's disease, Amyloidosis, Ankylosing spondylitis, Anserine bursitis, Avascular necrosis, **B**ehcet's syndrome, Bicipital tendinitis, Blount's disease, Brucellar spondylitis, Bursitis, **C**alcaneal bursitis, Calcium pyrophosphate dihydrate (CPPD) crystal deposition disease, Caplan's syndrome, Carpal tunnel syndrome, Chondrocalcinosis, Chondromalacia patellae, Chronic synovitis, Chronic recurrent multifocal osteomyelitis, Churg–Strauss syndrome, Cogan's syndrome, Corticosteroid-induced osteoporosis, Costosternal syndrome, CREST syndrome, Cryoglobulinemia, **D**egenerative joint disease, Dermatomyositis, Diabetic finger sclerosis, Diffuse idiopathic skeletal hyperostosis (DISH), Discitis, Discoid lupus erythematosus, Drug-induced lupus, Duchenne's muscular dystrophy, Dupuytren's contracture, **E**hlers–Danlos syndrome, Enteropathic arthritis, Epicondylitis, Erosive inflammatory osteoarthritis, Exercise-induced compartment syndrome, **F**abry's disease, Familial Mediterranean fever, Farber's lipogranulomatosis, Felty's arthritis, Fibromyalgia, Fifth's disease, Flat feet, Foreign body synovitis, Freiberg's disease, Fungal arthritis, **G**aucher's disease, Giant cell arteritis, Gonococcal arthritis, Goodpasture's syndrome, Gout, Granulomatous arteritis, **H**emarthrosis, Hemochromatosis, Henoch–Schönlein purpura, Hepatitis B surface antigen disease, Hip dysphasia, Hurler syndrome, Hypermobility syndrome, Hypersensitivity vasculitis, Hypertrophic osteoarthropathy, **I**mmune complex disease, Impingement syndrome, **J**accoud's arthropathy, Juvenile ankylosing spondylitis, Juvenile dermatomyositis, Juvenile rheumatoid arthritis, **K**awasaki disease, Kienbock's disease, **L**egg–Calve–Perthes disease, Lesch–Nyhan syndrome, Linear scleroderma, Lipoid dermatoarthritis, Lofgren's syndrome, Lyme disease, **M**alignant synovioma, Marfan's syndrome, Medial plica syndrome, Metastatic carcinomatous arthritis, Mixed connective tissue disease (MCTD), Mixed cryoglobulinemia, Mucopolysaccharidosis, Multicentric reticulohistiocytosis, Multiple epiphyseal dysplasia, Mycoplasmal arthritis, Myofascial pain syndrome, **N**eonatal lupus, Neuropathic arthropathy, Nodular panniculitis, **O**chronosis, Olecranon bursitis, Osgood–Schlatter's disease, Osteonecrosis, Osteoporosis, Overlap syndrome, **P**achydermoperiostosis, Paget's disease of bone, Palindromic rheumatism, Patellofemoral pain syndrome, Pellegrini–Stieda syndrome, Pigmented villonodular synovitis, Piriformis syndrome, Plantar fasciitis, Polyarteritis nodosa, Polymyalgia rheumatica, Polymyositis, Popliteal cysts, Posterior tibial tendinitis, Pott's disease, Prepatellar bursitis, Prosthetic joint infection, Pseudoxanthoma elasticum, Psoratic arthritis, **R**aynaud's phenomenon, Reactive arthritis/Reiter's syndrome, Reflex sympathetic dystrophy syndrome, Relapsing polychondritis, Retrocalaneal bursitis, Rheumatic fever, Rheumatoid arthritis, Rheumatoid vasculitis, Rotator cuff tendinitis, **S**acroiliitis, Salmonella osteomyelitis, Sarcoidosis, Saturnine gout, Scheuermann's osteochondritis, Scleroderma, Septic arthritis, Seronegative arthritis, Shigella arthritis, Shoulder–hand syndrome, Sick cell arthropathy, Sjogren's syndrome, Slipped capital femoral epiphysis, Spinal stenosis, Spondylolysis, Staphylococcus arthritis, Stickler syndrome, Subacute cutaneous lupus, Sweet's syndrome, Sydenham's chorea, Syphilitic arthritis, Systemic lupus erythematosus (SLE), **T**akayasu's arteritis, Tarsal tunnel syndrome, Tennis elbow, Tietze's syndrome, Transient osteoporosis, Traumatic arthritis, Trochanteric bursitis, Tuberculosis arthritis, Arthritis of **U**lcerative colitis, Undifferentiated connective tissue syndrome (UCTS), Urticarial vasculitis, **V**iral arthritis, **W**egener's granulomatosis, Whipple's disease, Wilson's disease, **Y**ersinia arthritis.

