American College of Rheumatology
Media Guide

A JOURNALIST’S GUIDE TO REPORTING ON RHEUMATOLOGY IN THE MEDIA
This media guide was created by the American College of Rheumatology and is designed to be used as a reference by members of the media who are reporting on rheumatic disease.

In this guide you will find:

- General information about the ACR, ARHP and Rheumatology Research Foundation
- Up-to-date prevalence statistics
- An overview of the most commons forms of rheumatic disease
- A glossary of terms frequently associated with rheumatic diseases
- Information on ACR initiatives such as the award winning Simple Tasks® campaign

If at any time, you need additional information, a quote for a story, or to interview one of our experts, please don’t hesitate to contact media relations staff at the ACR.

Rheumatologists are the experts in the diagnosis and management of rheumatic diseases (e.g., rheumatoid arthritis and lupus). If caught early, and treated appropriately, long-term complications (such as joint damage and disability) can be prevented.

The ACR can help you schedule interviews on any number of topics related to rheumatic disease. For more information, or to connect with an expert, please contact the PR department at pr@rheumatology.org or (404) 633-3777
ABOUT THE ACR, ARHP AND RHEUMATOLOGY RESEARCH FOUNDATION

ABOUT THE ACR
The American College of Rheumatology is an international professional medical society that represents more than 9,000 rheumatologists and rheumatology health professionals around the world. Its mission is to advance rheumatology through programs of education, research, advocacy and practice support that foster excellence in the care of people arthritis, rheumatic and musculoskeletal diseases.

The ACR/ARHP Annual Meeting is the premier meeting in rheumatology. In 2013, the meeting attracted approximately 11,800 professional attendees, with an estimated 15,000 total attendees. The ACR provides professional education for its members through several venues. The ACR/ARHP Annual Meeting, held each fall, is the premier scientific meeting devoted to the rheumatic diseases. This meeting draws thousands of rheumatologists and rheumatology health professionals from around the world. Professional meetings and online courses round out the ACR’s educational offerings.

The ACR publishes Arthritis & Rheumatism, the premier scientific journal for research in the rheumatic diseases. Arthritis Care & Research is published by the ARHP. This journal focuses on the health services and clinical aspects of rheumatology.

ABOUT ARHP
The Association of Rheumatology Health Professionals, a division of the American College of Rheumatology, is a professional membership society composed of non-physician health care professionals specializing in rheumatology, such as advanced practice nurses, nurses, occupational therapists, physical therapists, psychologists, social workers, epidemiologists, physician assistants, educators, clinicians, researchers, research coordinators and office staff.

ABOUT THE RHEUMATOLOGY RESEARCH FOUNDATION
The mission of the Rheumatology Research Foundation is advancing research and training to improve the health of people with rheumatic diseases.

Since its founding in 1985, the Foundation has awarded $100 million to more than 2,200 recipients. The Foundation has committed nearly $13.3 million in research and training funding in 2014. The Foundation offers an extensive awards program with research and education opportunities for clinicians, students, health professionals, researchers and academic institutions and is the largest private funding source of rheumatology training and research programs in the United States.

The Rheumatology Research Foundation is classified as a 501 (c)(3) organization. All donations to the Foundation are tax deductible. The Foundation has received consecutive 4-star ratings from Charity Navigator, America’s largest and most-utilized independent evaluator of charities.
WHAT IS A RHEUMATOLOGIST?

Just as oncologists treat cancer and cardiologists care for the heart, rheumatologists are the specialists trained to diagnose and treat rheumatic diseases. Rheumatologists treat over 100 different forms of rheumatic diseases, arthritis and other diseases of the joints, muscles and bones. In addition to specializing in the diagnosis and treatment of these diseases, rheumatologists are care leaders, cost savers, and the solution for millions of Americans.

THE SPECIALIST
Rheumatologists complete four years of medical school, three years of training in either internal medicine or pediatrics, and two to three years of specialized training in rheumatology.

A rheumatologist is specially trained to identify rheumatic diseases – such as rheumatoid arthritis, lupus, gout, scleroderma, juvenile arthritis, and Sjögren’s syndrome – and to facilitate treatment with the aim of achieving disease remission as soon as possible. To do this, rheumatologists must have comprehensive knowledge of the immune system and be experts in the administration of complex treatments (such as the biologics often used to treat cancer patients).

THE CARE LEADER
Rheumatologists understand the impact of rheumatic diseases on the entire body. These diseases are chronic, so rheumatologists see their patients frequently and over a number of years – with many patients looking to them as care leaders.

Additionally, the expertise of rheumatologists is critical to educating and guiding referring physicians in identifying the red flags of a rheumatic disease and assisting in ongoing long-term patient care.

Rheumatologists involve a number of health care professionals in patient-care teams. Patients with a rheumatic disease often seek guidance on a number of physiological and emotional health concerns, as well as practical issues. Rheumatologists spearhead teams that can include nurse practitioners, physical therapists, psychologists and social workers.

THE COST SAVER
Early and appropriate treatment by rheumatologist can delay, slow or even stop disease progression. When appropriate treatment is started early, medical costs, disability and work limitations due to rheumatic diseases can all be reduced.

Recent data indicates arthritis and other rheumatic diseases led to $127.8 billion in medical costs in the United States, nearly a quarter more than the $104 billion in costs for cancer care. With early and appropriate referral to a
rheumatologist, a person’s treatment plan can be specifically tailored by pinpointing which therapies are most effective – saving money and valuable time on unnecessary, poorly applied and possibly ineffective treatments.

THE SOLUTION
For the millions of Americans suffering from rheumatic diseases, rheumatologists can provide answers, relief and hope. The first weeks and months following the onset of rheumatic disease symptoms is called the window of opportunity – the short period of time in which patients who get appropriate treatment can diminish the long-term complications of their rheumatic disease. With diseases so complex and debilitating, seeing a rheumatologist during the window of opportunity is critical.

People with inflammatory rheumatic diseases face joint and organ destruction, severe pain, disability and even death. Rheumatologists, unlike any other health care providers, are equipped with the tools to detect and treat these diseases – providing solutions to help these patients live life to the fullest.

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ONLINE: HTTP://WWW.SIMPLETASKS.ORG/WHAT-IS-A-RHEUMATOLOGIST
## Common Rheumatic Diseases and Conditions

There are more than 100 rheumatic diseases, including common degenerative conditions (such as osteoarthritis) and less common diseases characterized by inflammation and autoimmunity (such as rheumatoid arthritis and lupus).

These diseases can affect joints, tendons, ligaments, bones and muscles. Some rheumatic diseases may also involve internal organs such as the kidneys or lungs. Common symptoms include joint pain, stiffness, swelling and weakness. Fatigue is another common problem, caused by chronic pain and disrupted sleep. Frequently these conditions lead to loss of function, which causes an inability to carry out activities of daily living. The table below highlights several conditions that are frequently encountered in rheumatology:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Osteoarthritis, Osteoporosis, Fibromyalgia</strong></td>
<td>Common diseases seen in primary care, which occasionally require rheumatology assistance for diagnosis and/or management.</td>
</tr>
<tr>
<td><strong>Carpal Tunnel Syndrome, Tendonitis, Bursitis, Low Back Pain, Spinal Stenosis</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Gout, Pseudogout</strong></td>
<td>Joint inflammation caused by the formation of crystals within joints.</td>
</tr>
<tr>
<td><strong>Rheumatoid Arthritis, Juvenile Idiopathic Arthritis</strong></td>
<td>Common forms of inflammatory arthritis seen in adults and children, respectively.</td>
</tr>
<tr>
<td><strong>Psoriatic Arthritis, Reactive Arthritis, Ankylosing Spondylitis, IBD-Associated Arthritis</strong></td>
<td>Seronegative (rheumatoid arthritis blood test negative) forms of arthritis. Autoimmune chronic joint inflammation, with additional manifestations outside the joints in some cases</td>
</tr>
<tr>
<td><strong>Polymyalgia Rheumatica, Giant Cell Arteritis</strong></td>
<td>Common inflammatory illness in patients over age 50.</td>
</tr>
<tr>
<td><strong>Lupus, Polymyositis, Sjögren’s Syndrome, Scleroderma, Antiphospholipid Syndrome</strong></td>
<td>Autoimmune disorders often referred to as the “connective tissue diseases.”</td>
</tr>
<tr>
<td><strong>Hepatitis C Infection, HIV Infection, Parvovirus Infection, Lyme Infection, Bacterial Infection of Joints</strong></td>
<td>Infections of particular importance to rheumatology.</td>
</tr>
<tr>
<td><strong>Paget’s Disease, Osteonecrosis, Glucocorticoid-induced Osteoporosis</strong></td>
<td>Conditions primarily affecting bone.</td>
</tr>
<tr>
<td><strong>Vasculitis</strong></td>
<td>Group of rare conditions causing blood vessel inflammation.</td>
</tr>
<tr>
<td><strong>Thyroid Disorder, Parathyroid Disorder, Vitamin D Deficiency, Cortisol Deficiency or Excess Disorders of Growth Hormone, Diabetes Mellitus, Electrolyte Disturbance</strong></td>
<td>Metabolic disturbances that may lead to musculoskeletal complaints.</td>
</tr>
</tbody>
</table>
FREQUENTLY USED TERMS

Analgesics - Medications in this category are used specifically for pain relief. Examples include acetaminophen and opiates (such as codeine, hydrocodone, oxycodone and morphine). Opioid analgesics are highly addictive and are therefore strictly regulated by both state and federal Drug Enforcement Agencies. A special license is required to prescribe this class of medications.

Acute - In a medical setting “acute” usually means of something which has a sudden onset, is severe and does not last long.

Anti-inflammatories – Medications in this category treat inflammation, and hence relieve inflammatory pain. Examples include aspirin and nonsteroidal anti-inflammatory drugs, commonly referred to as NSAIDs, such as naproxen, ibuprofen, meloxicam, celecoxib, nabumetone and diclofenac. Some of these agents are available for over-the-counter use. Stomach ulcers and increased risk of bleeding are major side effects of these medications. They may also reduce kidney function and increase blood pressure in some patients. Elderly patients have a much higher risk of problems related to these drugs.

Arthritis - Means disease of or damage to the joints. Although the ending – it is implies inflammation, in some forms of arthritis there is very little inflammation present.

Autoimmune disease – A disorder of the body's defense mechanism (immune system), in which antibodies and other components of the immune system attack the body's own tissues.

Biologics - Medications in this category are produced using recombinant DNA technology. They are generally monoclonal antibodies or fusion proteins that target specific immune receptors, or soluble products such as cytokines. Examples include TNF blockers (etanercept, adalimumab, infliximab, golimumab and certolizumab), rituximab, tocilizumab, abatacept, anakinra and canakinumab. Biologics greatly increase the risk for infection. Screening for tuberculosis, hepatitis B virus and hepatitis C virus is necessary prior to prescribing these medications.

Cartilage - Is the smooth, tough material with a slippery surface which covers the bone ends. It acts as a shock absorber and allows smooth movement between bones.

Corticosteroid - Corticosteroids – These medications acutely reduce pain caused by inflammation. Corticosteroids (also known as glucocorticoids) exert their effects by decreasing immune cell activation and function and by reducing the release of inflammatory mediators called cytokines. Examples include prednisone, methylprednisolone and triamcinolone. Topical, intravenous, and injectible formulations are available. Acute painful arthritis is often managed by injecting corticosteroids directly into the affected joint. Chronic corticosteroid use is associated with numerous side effects, including susceptibility to infection, elevated blood sugar, cataracts,
glaucoma, osteoporosis, psychiatric disturbance, weight gain, and fluid retention. Side effects are proportional to dose and duration of treatment, so every effort is made to use these medications judiciously.

**Connective tissue** - This term loosely describes the tissues which hold the body together. Connective tissue is present in all organs, so the term “Connective Tissue Diseases” describes a group of diseases which affect a wide range of different body systems.

**Chronic** - in a medical setting “chronic” refers to a condition which persists for a long time.

**DMARDs** - DMARDs are prescribed to quell inflammation that can cause permanent damage to the joints and organs. When prescribed early in the disease process, DMARDs can often prevent irreparable damage from occurring.

**Fibromyalgia** - Fibromyalgia is a common health problem that causes widespread pain and tenderness (sensitive to touch). The pain and tenderness tend to come and go, and move about the body. Most often, people with this chronic (long-term) illness are fatigued (very tired) and have sleep problems. It can be hard to diagnose fibromyalgia.

**Juvenile idiopathic arthritis (JIA)** - There are many terms used to describe a child with chronic arthritis. These include juvenile rheumatoid arthritis, juvenile chronic arthritis and juvenile idiopathic arthritis. Several types of arthritis, all involving chronic (long-term) joint inflammation, fall under the JIA heading. This inflammation begins before patients reach the age of 16, and symptoms last from 6 weeks to 3 months to be called chronic. JIA may involve one or many joints, and cause other symptoms such as fevers, rash and/or eye inflammation.

**Gout** - Gout is a painful and potentially disabling form of arthritis that has been around since ancient times. The first symptoms usually are intense episodes of painful swelling in single joints, most often in the feet, especially the big toe. The swollen site may be red and warm. Treatments are available to control most cases of gout. However, diagnosing gout can be hard, and treatment plans often must be tailored for each person.

**Immune system** - The immune system is the body’s defense system against infection and other problems. It consists of an integrated network of cells and the chemicals they produce which constantly patrol the body looking for problems. When such a problem is encountered the immune system reacts by producing inflammation, the aim of which is to eliminate the infection (or other abnormality) from the body.

**Immunosuppressants** - these medications inhibit the activation and function of immune cells, thereby diminishing auto-immunity. Examples include methotrexate, leflunomide, cyclophosphamide, azathioprine, mercaptopurine, mycophenolate mofetil, cyclosporine A, tacrolimus and sirolimus. Immunosuppressants increase susceptibility to infection. They require periodic laboratory monitoring to avoid liver, kidney and bone marrow toxicity.
Inflammation - When the immune system reacts to infection or some other stimulus, the whole process is called inflammation. There is often pain, swelling, redness, and warmth of the affected part.

-itis - at the end of a word means inflammation of something e.g. tonsillitis

Joints - are the places where bones meet. They allow flexibility. There are different types of joint. In “synovial” joints the surfaces where the bones meet are covered in cartilage and the joint is enclosed in a capsule which is lined with synovium.

Ligaments - are tough, fibrous bands which hold two bones together in a joint.

Lyme Disease - Lyme disease is an infection spread by the bite of certain types of ticks. If caught and treated early, the infection most often clears quickly. If not found until the later stages of infection, people with Lyme disease are more likely to still have symptoms (what you feel) after treatment. These include fatigue (feeling very tired), poor sleep, and muscle and joint pain.

Lupus - Lupus is a chronic disease that causes inflammation — pain and swelling. It can affect the skin, joints, kidneys, lungs, nervous system and other organs of the body. Most patients feel fatigue and have rashes, arthritis (painful and swollen joints) and fever.

NSAIDS - NSAIDs are used to relieve pain and inflammation associated with arthritis and related conditions. They are also have many uses outside of arthritis treatment, such as lowering fevers, easing tooth aches, and relieving muscle aches from strenuous physical activity or the flu.

Osteoarthritis (OA) - OA is a frequently slowly progressive joint disease typically seen in middle-aged to elderly people. The disease occurs when the joint cartilage breaks down often because of mechanical stress or biochemical alterations, causing the bone underneath to fail. OA can occur together with other types of arthritis, such as gout or rheumatoid arthritis. OA tends to affect commonly used joints such as the hands and spine, and the weight-bearing joints such as the hips and knees.

Psoriatic Arthritis (PsA) - Psoriatic arthritis is a type of arthritic inflammation that occurs in about 15 percent of patients who have a skin rash called psoriasis. This particular arthritis can affect any joint in the body, and symptoms vary from person to person. Research has shown that persistent inflammation from psoriatic arthritis can lead to joint damage. Fortunately, available treatments are effective for most people.

Prognosis - is the medical term for outlook, or a prediction of the likely outcome.

Rheumatoid Arthritis - RA is a chronic disease that causes pain, stiffness, swelling and limited motion and function of many joints. While RA can affect any joint, the small joints in the hands and feet tend to be involved most often. Inflammation sometimes can affect organs as well, for instance, the eyes or lungs.
**Rheumatism** - is a more general term used in the past to describe any pain in or around your bones, muscles and joints.

**Synovium** - is the inner layer of the joint capsule. It produces synovial fluid to lubricate the joint. This synovial fluid is produced by normal joints. When arthritis develops in a joint the synovial membrane becomes thickened and it produces large amounts of fluid. This is what causes the swelling of the joint.

**Tendons** - are strong fibrous cords that connect muscles to bones.
THE PREVALENCE OF RHEUMATIC DISEASES

OVERALL PREVALENCE OF ARTHRITIS AND RHEUMATIC DISEASES
In an November 2013 issue of Morbidity and Mortality Weekly Report, the Centers for Disease Control and Prevention announced data estimating that 52.5 million U.S. adults suffer from arthritis - equating to about 23 percent¹.

PREVALENCE AMONG SPECIFIC RACIAL AND ETHNIC GROUPS
The CDC also reported that arthritis affects an estimated 3.1 million Hispanics in the United States. Published in the Feb. 18 issue of Morbidity and Mortality Weekly Report, the study presents key findings among seven Hispanic and Latino subgroups including Puerto Ricans, Mexicans, Dominicans, and Cubans. Highlights included:

- Puerto Ricans reported the highest age-adjusted prevalence of arthritis (21.8 percent) and Cubans/Cuban Americans the lowest (11.7 percent)²
- Among all subgroups of Hispanics with arthritis, at least 20 percent of people with arthritis reported one or more of the three arthritis-attributable effects and limitations including activity limitations, work limitations, and severe joint pain²
- For most subgroups, arthritis prevalence was highest among people 65 years and older, women, and people who were obese²
- Overall, an estimated 875,000 Hispanics ages 18-64 reported arthritis-attributable effects²
- Overall, an estimated 1.2 million Hispanics reported severe joint pain²

ADDITIONAL STATISTICS
The National Arthritis Data Workgroup reviewed data from national and regional surveys to estimate national prevalence rates of various rheumatic diseases based on 2005 U.S. Census data.

The results were published in an article titled, "Estimates of the Prevalence of Arthritis and Other Rheumatic Conditions in the United States" in the January 2008 issue of Arthritis & Rheumatism. Part one of the article was published on pages 15 – 25 and part two was published on pages 26 – 35. A summary of the article is as follows:
- Rheumatoid arthritis – 1.3 million U.S. adults
- Juvenile arthritis – 294,000 people in the U.S.
- Spondylarthritides – 0.6 to 2.4 million U.S. adults over 15
- Systemic lupus erythematosus – 161,000 to 322,000 U.S. adults
- Systemic sclerosis – 49,000 U.S. adults
- Sjögren’s syndrome – 0.4 to 3.1 million adults
- Clinical osteoarthritis – 27 million U.S. people age 25 and older
- Polymyalgia rheumatica – 711,000 people in the U.S.
- Giant cell arteritis – 228,000 people in the U.S.
- Gout – three million people in the U.S.
- Fibromyalgia – five million people in the U.S.
- Carpal tunnel syndrome – four to 10 million people in the U.S.
- Low back pain – 59 million within the three months prior to the study
- Neck pain – 30.1 million within the three months prior to the study

Online:

http://www.cdc.gov/mmwr/PDF/wk/mm5939.pdf
http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6006a2.htm?s_cid=mm6006a2_w
http://www.rheumatology.org/ACR/about/newsroom/prevalence/prevalence-one.pdf
http://www.rheumatology.org/ACR/about/newsroom/prevalence/prevalence-two.pdf
THE SIMPLE TASKS® CAMPAIGN

Millions of Americans are living with painful, debilitating, and costly rheumatic diseases. These diseases can make even the simplest tasks — such as eating, brushing your teeth and driving a car — impossible. The first weeks and months following the onset of rheumatic disease symptoms are known as the "window of opportunity," and it is crucial that patients get appropriate treatment in that time period to avoid lasting complications.

Appropriate treatment for these complex diseases should be administered by a rheumatologist – the only specialist specifically trained in the diagnosis and treatment of rheumatic diseases. Unlike any other health care providers, rheumatologists are equipped with the tools to detect and treat rheumatic diseases. Rheumatologists’ training and practice equips them to diagnose patients quickly and maximize the "window of opportunity" – dramatically improving a patient’s prognosis.

In September, 2011, the American College of Rheumatology launched the Simple Tasks campaign to educate lawmakers, administration officials, think tanks, advocacy groups, physicians and physician groups on the importance of rheumatology as well as to increase the understanding of the work of rheumatologists and lay a foundation of awareness that creates support for more favorable public policy.

Appropriate and timely referrals, legislation that ensures access to rheumatologists, supporting research and initiatives to grow the workforce, and understanding the importance of the practice of rheumatology are all crucial to ensuring that more people with rheumatic diseases are treated within the "window of opportunity." However, many of the influential people and groups responsible for making significant decisions about these health care issues are not equipped with enough information about rheumatic diseases and rheumatologists to make decisions that positively impact the rheumatology community.

By increasing the visibility of rheumatic diseases and of the specialists who treat them, it is the ACR’s hope that these influential people and groups will recognize the value of rheumatology, understand the issues affecting this community, and make decisions that support rheumatology and the patients served by the rheumatology health care team.

Join the American College of Rheumatology and Americans in fighting the devastating effects of rheumatic diseases. Visit www.simplетasks.org to find your window of opportunity to help.
THE LUPUS INITIATIVE

The Lupus Initiative® is an educational program led by the ACR that aims to increase medical professionals’ understanding and awareness of lupus, a devastating and life-threatening autoimmune disease. The Lupus Initiative is funded in part by the U.S. Department of Health and Human Services through its Office of Minority Health.

The Lupus Initiative: provides medical professionals, educators and students with comprehensive, user-friendly educational resources to help them diagnose, treat and manage lupus, as well as provide culturally-competent and patient-centered care.

Materials are available online and are designed to be easily incorporated into a medical professional’s hectic schedule or a professor’s packed medical curriculum. All resources were developed with a national consortium of partners that includes lupus experts from a range of medical specialties, as well as leaders in research, patient awareness academia, and the reduction of health disparities.

Available materials include:

- CME/CE courses
- Power point slides for medical school lectures
- Interactive case studies
- Video series
- Educational patient resources, available in both English and Spanish

Why is important to focus on lupus?

Lupus is a complex, chronic autoimmune disease that affects up to 1.5 million people across the US. It causes the body’s immune system to form antibodies that can attack virtually any organ or tissue in the body. It disproportionately affects women and people of color, most often during prime childbearing years. People of color have mortality rates two to three times higher than Caucasians.

Those most likely to be sick are also more likely to be uninsured and less likely to have access to the care they need.

Lupus is very hard to diagnose because it can involve a range of symptoms that are common to multiple diseases. According to a survey of Lupus Foundation of America members, more than half of lupus patients suffered for at least four years and saw three or more physicians before obtaining a correct diagnosis.
The more a medical professional knows about lupus, the more likely he or she is to identify its signs and symptoms early and accurately to diagnose the disease or refer a patient to a specialist.

The Lupus Initiative is devoted to ensuring the early and accurate diagnosis, effective treatment and management of patients with lupus, regardless of age, gender, race, ethnicity or socioeconomic status, so that they may lead happy, healthy and productive lives.

To learn more about The Lupus Initiative, visit [www.thelupusinitiative.org](http://www.thelupusinitiative.org)