Rheumatic diseases and rheumatologists

Rheumatic diseases, arthritis and other diseases of the muscles, joints and bones are common and have tremendous impact on the health and well-being of nearly 50 million Americans. The most severe of these — inflammatory rheumatic diseases — cause joint and organ destruction, severe pain, disability and even death.

People afflicted with rheumatic diseases are cared for by rheumatologists who, unlike any other health care providers, are equipped with the tools to detect and treat them.

While rheumatologists treat over 100 different forms of rheumatic disease and arthritis, this paper details the problems caused by the most severe forms of these — inflammatory rheumatic diseases such as rheumatoid arthritis, lupus and gout — and will highlight how rheumatologists are providing health care solutions for the millions of Americans suffering from — as well as advancing research aimed at treating and curing, and alleviating the economic and societal burdens created by — these diseases.

Just as oncologists treat cancer and cardiologists care for the heart, rheumatologists are the specialists specifically trained to identify rheumatic diseases, facilitate appropriate treatment with the aim of achieving remission as early as possible, and consult with other physicians to help them determine which patients need the care of a rheumatologist — all with the goal of dramatically improving a patient’s prognosis and quality of life.

In short, rheumatic diseases are not the only diseases rheumatologists treat, but rheumatologists are the only physicians qualified to treat rheumatic diseases.

Rheumatic diseases often strike people in the prime of life and can be crippling and life-changing.
Imagine not being able to grip things. Everything you pick up runs the risk of being dropped. Jars can’t be opened, children can’t be held, your shoes are slip on or remain untied. This is often life with a rheumatic disease.

Life-changing, painful, deforming, costly, crippling, deadly — these are serious words to describe serious diseases. Contrary to notions that “aches and pains” are just a normal part of aging, the intense joint pain, swelling, stiffness and fatigue experienced by people with rheumatic diseases, such as rheumatoid arthritis and lupus, often occur in people who are in the prime of their lives and often abruptly interrupt education, careers, child-rearing and other essential daily activities.

Of the 50 million1 with diseases of the muscles, joints and bones, rheumatic diseases affect over 11 million Americans.2 They not only cause inflammation and damage to joints, but can also cause serious damage to other organs of the body, development of co-existing diseases, disability, and even death. People with rheumatic diseases often require complex and powerful medications and need the care of experts who specialize in the use and management of these medications. At the center of this care, helping people along the entire spectrum of rheumatic disease management, are rheumatologists. And, for the millions of Americans suffering with rheumatic diseases, rheumatologists can provide answers, relief and hope.

Simply put: rheumatic diseases often strike people in the prime of life and can be crippling and life-changing. Rheumatologists are the specialists devoted to effectively diagnosing, managing and treating these diseases to help patients avoid serious co-existing diseases, disability and death.

The severe impact of rheumatic diseases

The numbers:

Millions of adults
Over 11 million American adults1 suffer from inflammatory rheumatic diseases, 1.3 million adults have RA,2 and between 161,000 and 322,000 adults have lupus.2

Hundreds-of-thousands of children
Nearly 300,000 American children3 suffer from rheumatic diseases, the most common of which is juvenile idiopathic arthritis, which can cause the same types of pain, disability and co-existing diseases that adults with rheumatic diseases often experience. Approximately one in every 250 children in the U.S. has some form of rheumatic disease or arthritis.4

One in 12 women
During their lifetime, 8.4 percent of women will develop a rheumatic disease.4 Women are two to three times more likely to be diagnosed with RA2 and nine out of 10 people who have lupus are women.4

One in 20 men
Five percent of men in the U.S. will develop a rheumatic disease during their lifetime.7

Strike in the prime of life
Inflammatory rheumatic diseases often strike people in the prime of their lives. For example, RA often develops between the ages of 35-506 and lupus between the ages of 15-44.3

The diseases:

Rheumatic diseases are autoimmune and inflammatory diseases that cause the immune system to attack a person’s joints, muscles, bones and organs. Rheumatic diseases are often lumped under the term arthritis — a term used to describe over 100 diseases and conditions. Under this umbrella of arthritis, there are over 30 inflammatory rheumatic diseases, including RA, lupus, gout, scleroderma, juvenile idiopathic arthritis, Sjögren’s syndrome, spondylarthritides, polymyalgia rheumatica, and several forms of systemic vasculitis (including giant cell arteritis). This list does not include the most common form of arthritis, known as osteoarthritis, which results in a breakdown of bone and cartilage in joints rather than inflammation.

The personal toll:

Pain and deformity
Rheumatic diseases can cause deformities so severe that those who suffer from them cannot bathe or dress themselves, while a simple task such as walking can cause pain and be difficult or even impossible.11

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Organ damage
Rheumatic diseases can cause damage to vital organs, including the lungs, heart, nervous system, kidneys, skin and eyes.6

Disability
Thirty percent of people with arthritis and rheumatic diseases attribute work limitations to them.10 And, rheumatic diseases, along with arthritis are a more frequent cause of activity limitation than heart disease, cancer or diabetes.7 Disability is even higher among patients with inadequately treated RA, with 60 percent being unable to work 10 years after the onset of their disease.12

Death
In their most severe form, rheumatic diseases can lead to life-threatening infections (such as pneumonia) and a significantly higher risk for developing other associated diseases including heart disease and cancer.11 For example, people with RA are twice as likely to die as people of the same age without RA in the general population.12 Without adequate therapy, the average life expectancy for a patient with RA may be shortened by three to seven years, and those with severe forms of RA may die as much as 10-15 years earlier than expected.14 As treatment for RA has improved, however, severe disability and life-threatening complications have decreased considerably and many people live relatively normal lives.

The cost to society:

Billions of dollars
The latest figures regarding arthritis and other rheumatic diseases show they led to $127.8 billion in medical costs in the U.S., more than the $124.6 billion in costs for cancer care.15
Rheumatic diseases attack the joints, muscles, bones and organs causing pain, inflammation, disability and death.

Why a rheumatologist is the solution:

Window of opportunity
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 long-term complications. Treatment early in the disease, even within the first 12 weeks for some, can prevent damage to joints and other organs, improve long-term function and increase the likelihood of achieving disease remission.

Benefits of appropriate treatment
When appropriate treatment is started early, medical costs, disability and work limitations due to rheumatic diseases can all be reduced.17

Experts in rheumatic diseases
Rheumatologists are specialists in diagnosing, managing and treating arthritis and rheumatic diseases. By virtue of their training in internal medicine and advanced specialized education in rheumatic diseases, they are uniquely qualified to deal not only with arthritis, but to recognize and treat the wide array of rheumatic disease symptoms that can affect almost any organ in the body. Rheumatologists are the experts in the diagnosis and treatment of all manifestations of these diseases.

With a deeper understanding of the physical, mental, economic and societal impacts of rheumatic diseases, the importance of supporting the specialty devoted to their diagnoses and treatment becomes evident. The following pages detail the problems caused by rheumatic diseases, the window of opportunity for patients to benefit from early and aggressive treatment, the role rheumatologists play in diagnosis and treatment, and your window of opportunity to support the more than 11 million U.S. adults and children suffering from these devastating diseases, as well as the specialists dedicated to treating them.

What you don’t know about rheumatic diseases

Rheumatic diseases are not just “aches and pains” and are not a normal part of aging. They strike adults of all ages, but most often strike in the prime of life and can be crippling, life-changing and life-threatening. These diseases also strike children and they carry the same destructive blow to a child’s health and wellbeing as they do to an adult’s.

Rheumatic diseases are inflammatory and autoimmune diseases
Autoimmune diseases act against a person’s own internal defense system, triggering the body to produce antibodies that actually attack healthy cells and tissues.

In the case of rheumatic diseases, the immune system attacks the patient’s joints, muscles, bones and organs causing pain, inflammation, life-altering disability and, in severe cases, can contribute to death.

There are over 30 autoimmune rheumatic diseases. Some of the most common are: RA, lupus, gout, scleroderma, juvenile idiopathic arthritis, Sjögren’s syndrome, spondyloarthritides, polymyalgia rheumatic and systemic vasculitis (including giant cell arteritis). Specific organs can be affected by rheumatic diseases. Some examples include:

Heart. Rheumatologists have led the way in discovering that the chronic inflammation associated with many rheumatic diseases can lead to increased risk of cardiovascular disease. For example, people with RA are twice as likely to develop heart disease than the average person. Additionally, having lupus greatly increases a person’s risk of developing cardiovascular disease and suffering from heart attacks. Nearly 40 percent of people with lupus develop prematurely hardened arteries, compared with 15 percent of their peers who do not have lupus. Other cardiac effects of rheumatic diseases include an increase in hardened arteries and its complications, as well as an increase in congestive heart failure.

Eyes. The eyes are dry, irritated and inflamed with Sjögren’s syndrome. More severe eye complications can be found in juvenile idiopathic arthritis and giant cell arteritis – both of which can lead to decreased or complete loss of vision.

Lungs. One in 10 people with RA will develop serious lung complications over the course of their disease due to damage to the lung tissue. People with scleroderma have an even higher risk for lung disease and can develop pulmonary fibrosis, a scarring of the lungs, which can lead to life-threatening breathing complications.

Nervous system. The deformity and damage to joints in RA can lead to nerve compression, which may lead to serious consequences. In fact, many rheumatic...
Rheumatic diseases can also cause other forms of neuropathy or damage to nerve fibers by a variety of mechanisms. Strokes are also more frequent in patients suffering from several of the rheumatic diseases including lupus, RA and giant cell arteritis.24

**Blood.** Anemia is a common symptom of most rheumatic diseases including lupus,27 RA24 and vasculitis.24

**Vascular system.** Giant cell arteritis increases the risk of aneurysms, which are enlarged blood vessels that may burst, causing life-threatening internal bleeding. Other forms of vasculitis, as well as scleroderma, RA and lupus can cause Raynaud’s syndrome – a cold-induced spasm of the blood vessels in the fingers and toes that may lead to painful ulcerations and even gangrene.23,21

**Skin.** Psoriatic arthritis is a particular type of rheumatic disease that occurs in some patients who have psoriasis, which is a chronic skin condition.26 Many other rheumatic diseases cause serious damage to the skin, including skin hardening suffered by patients with scleroderma.

Additionally, rheumatic diseases can contribute to other serious co-existing diseases and infections, especially if not treated properly. Some examples include:

- Serious infections, such as pneumonia, account for one-third of lupus-related deaths.25
- Just a year after a patient has been diagnosed with RA, the risk of heart attack is 60 percent higher than someone without RA.24
- Patients with psoriatic arthritis are 50 percent more likely than the general public to develop diabetes.23

- Scleroderma can cause scarring of the tissues around the heart, which can lead to abnormal heartbeats and congestive heart failure.24
- Scleroderma can affect a person’s kidney function and lead to kidney failure and dialysis.24
- Osteoporosis is a major health problem in patients with rheumatic diseases, due both to the effects of the diseases, as well as their treatments.25
- Many forms of rheumatic diseases, as well as their treatments, are associated with an increased risk of cancer, especially lymphoma.24

**Number one cause of disability in the United States**

People with rheumatic diseases are not merely suffering from the inability to participate in leisure activities; they often struggle with life’s most simple tasks, such as getting out of bed in the morning, caring for their children, cooking meals, driving an automobile, dressing themselves and getting through a work day. In fact, inflammatory rheumatic diseases with arthritis, cause more disability in America than heart disease, cancer or diabetes.2

In one recent survey of people with RA, researchers found over a three-month period, employees with RA missed an average of two-to-three weeks of work.37 Another study noted many employees with RA not only altered their working hours, but also changed their job or pursued a different career altogether.37

Rheumatic diseases are life-threatening

People with rheumatic diseases have to face both the frightening idea of being diagnosed with a potentially crippling disease, as well as the reality they might die earlier than expected,24 which can be overwhelming and devastating. Every year thousands of Americans die from lupus complications.26 Additionally, mortality rates for people with diffuse scleroderma are five-to-eight times greater than people of the same age and gender without the disease.24 Life expectancy is also shorter among people with RA; improvements in the life expectancy seen in the general population in the last 50 years have not been achieved to the same extent in those living with RA. The most recent North American study of mortality among people with RA found a standardized mortality ratio of 2.26 among people with RA compared to the general population. That is, people with RA are more than two times more likely to die than people of the same age in the general population.28

Women and minorities are disproportionately affected

It is estimated that one in 12 women will develop a rheumatic disease during her lifetime, and she is likely to be affected in the prime of her life. Left untreated, it can affect all aspects of a woman’s life – from dating and starting a family to raising children and being a productive worker. Ninety percent of people with lupus are women between the ages of 15 and 45,41 and the risk of miscarriages, stillbirths and premature deaths is disproportionately affected

Close to one out of every three employees with RA leaves the workforce due to work limitations.
It is not just women with lupus who are disproportionally affected. In fact, many rheumatic diseases strike women more than men. Of the 1.3 million American adults with RA, 75 percent are women. Additionally, polymyalgia rheumatica affects women twice as often and scleroderma affects women at least four times as often as men.

Minorities are also disproportionally affected. Data provided by the Centers for Disease Control and Prevention, the Lupus Foundation and the Lupus Initiative indicate rheumatic diseases disproportionately affect minorities. African-American women are three times more likely than Caucasian women to have lupus and develop severe symptoms, with as many as one in every 250 affected by this form of rheumatic disease alone. It is also twice as prevalent among Asian-American and Latina women compared to Caucasian women. Scleroderma is also more commonly found in African-Americans. Among those with this particular rheumatic disease, African-Americans are more likely to develop severe lung complications.

The toll is beyond the physical

Rheumatic diseases not only cause physical damage, but also take a severe mental and emotional toll on the people who suffer from them. It is often this mental and emotional toll that places a burden on a person’s family, intimate, social and business relationships.

Depression is one of the most common co-existing conditions of rheumatic diseases, resulting from the stress of living with a chronic disease and chronic pain. Some psychiatric and medical studies state 15 percent of those with a chronic illness, such as a rheumatic disease, suffer from clinical depression; others place this figure as high as 60 percent. In fact, people with RA have been found to be twice as likely as other individuals to experience depression.

In addition to depression, people living with chronic diseases and chronic pain often suffer from anxiety disorders. One recent study showed people with chronic neck and back pain (just two of the areas that can be affected by rheumatic diseases) are twice as likely to develop an anxiety disorder as those without.

Also connected to living with a chronic, painful disease, are intimacy issues. Recent studies have shown the higher a person’s level of pain, physical disability and depression, the greater the effect on his or her sex drive and desire to be intimate. Additionally, some rheumatic diseases can cause physical roadblocks to intimacy (for example, men who have scleroderma often experience erectile dysfunction). Given the impact rheumatic diseases have on a person, this integral part of being human can be negatively impacted.

Outside of depression, anxiety and intimacy issues, rheumatic diseases can cause cognitive difficulties. These cognitive issues can affect a person’s self-esteem, ability to communicate and ability to function in work, social and family environments. One example of this is called the “lupus fog.” The lupus fog can cause subtle changes in a person’s memory and ability to concentrate, as well as lapses in awareness, impairment in recall, difficulty problem-solving, trouble with calculations, difficulty in planning and/or trouble with visual-spatial functioning.

There is a window of opportunity

The first weeks and months following rheumatic disease symptom onset is known as “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.

If left untreated, rheumatic diseases cause progressive damage to affected organs and joints. RA, for example, causes joint pain, difficulty in the use of the joints and ultimately, destruction and deformity of the joints, and can cause serious damage to other organs as well. There is a substantial body of research demonstrating early and aggressive treatment significantly improves patient outcomes with findings as compelling as: patients who receive treatment within 12 weeks of disease onset report nearly 30 percent less pain after 36 months than those patients who receive treatment after 12 weeks.

Rheumatologists: the solution for over 11 million Americans

Diseases so complex and debilitating require a highly-trained and experienced specialist. Unlike any other health care provider, 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,” which can dramatically improve a patient’s prognosis and quality of life.

Early and appropriate referral to a rheumatologist not only improves overall health of patients with rheumatic diseases, it helps avoid potentially unnecessary tests, (e.g., blood tests, X-rays, CT scans, MRIs) and surgery in the quest for a diagnosis and treatment plan.
A rheumatologist is specially trained to identify rheumatic diseases and facilitate treatment with the aim of achieving remission as soon as possible. They have access to highly-effective medications and understand the importance of regular monitoring.

Furthermore, rheumatologists specially tailor patient treatment by pinpointing which treatments are most effective – saving money on unnecessary, poorly applied and possibly ineffective treatments and saving precious time for patients who have only a short window of opportunity to get their disease treated properly.

**Rheumatologists are uniquely trained**

A rheumatologist is a physician who treats rheumatic diseases, arthritis and other diseases of the muscles, joints and bones. To ensure the most in-depth training in internal medicine and rheumatic diseases, 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.

After completing their training, rheumatologists must pass a rigorous exam conducted by the American Board of Internal Medicine or the American Board of Pediatrics to be certified. Once certified, a rheumatologist is required to complete an extensive recertification process every 10 years.

**Rheumatologists serve as care leaders**

With their comprehensive knowledge of the immune system, rheumatologists understand how rheumatic diseases affect the entire body from head to toe. As rheumatic diseases are chronic, rheumatologists see their patients frequently and help them understand and manage a variety of health matters – from medications to physical and occupational therapy, surgery, mental health needs, pregnancy and common infections. The expertise of rheumatologists is critical to educating and guiding primary care providers in offering appropriate care by providing subspecialty consultation and management of rheumatic diseases. In providing this expertise and care, rheumatologists involve other health professionals in their patient-care teams, including physician’s assistants, nurse practitioners, physical and occupational therapists, psychologists and social workers. Rheumatology health professionals support patient care by addressing health and practical patient concerns in the home or workplace.

**Rheumatologists advance the medical field**

Rheumatologists have made major contributions to the body of knowledge concerning the immune system for nearly a century. This knowledge has guided the development and implementation of treatments that correct immune abnormalities. They have advanced patient care by driving research leading to the development of new drugs and treatments for rheumatic diseases. Many rheumatologists are experts in designing, performing and interpreting clinical studies, and their work has resulted in many of the most successful therapies currently in use – therapies not even approved 15 years ago. Finally, the expertise of rheumatologists in clinical trial design and outcomes research has been a model for all other medical subspecialties.

One of the most notable advancements in rheumatology has been the development of medications that address the fundamental biologic processes involved in causing these diseases, not just their symptoms. In the past, rheumatic diseases were often treated with medications that relieved pain, but did not stop ongoing joint and other organ damage. Today, the new and complex medications pioneered by rheumatologists are treating the causes of the disease and providing patients with rheumatic diseases a chance to get their lives back. Additionally, many treatments originally developed for rheumatic diseases have since expanded to other diseases – demonstrating just how important rheumatologists are to advancing the general field of health science.

**Rheumatologists are experts in the administration of complex treatments**

Rheumatologists are the most familiar with the latest research, interventions and medications to control rheumatic diseases. The unique expertise of the rheumatologist prevents unnecessary testing and allows for more specific therapy, which ultimately means fewer side effects for patients and lower costs of care and treatment for the healthcare system.

Rheumatic diseases often require highly toxic medications (such as chemotherapy, which is commonly known for its ability to fight cancer). These medications are powerful healers, but have potentially dangerous effects and must be carefully administered and monitored.
Due to their advanced and specialized education and training — as well as their dedication to discovering, understanding and utilizing the latest advancements in treatment — rheumatologists are the best equipped specialists to prescribe the appropriate medications for each particular rheumatic disease and to monitor and respond to potential side effects.

**Rheumatologists decrease disability and death**

Through reducing the severity of patient symptoms, rheumatologists allow patients to keep or attain employment. In addition, they prevent the kind of deformities that can lead to permanent disability and disease progression and co-existing diseases that can lead to death.

**Rheumatologists provide care creating societal benefits**

Although the demand for rheumatology services is expected to increase by 46 percent through the year 2025, it is expected that the number of practicing rheumatologists in the same period will only increase by 1.2 percent. This shortfall in manpower is unacceptable to the patients who suffer from rheumatic diseases and to the rheumatologists who treat them.

Through education, fundraising, grant making, mentoring medical students and lobbying, rheumatologists consistently work to ensure their patients have access to the specialty care they need and the best and brightest in medicine are attracted to this specialty.

More specifically, the Rheumatology Research Foundation — the charitable arm of the American College of Rheumatology, which serves as the specialty society for rheumatologists and rheumatology health professionals — has funneled more than $7.5 million into the training of future rheumatologists over the past 10 years.

Without proper treatment, people with rheumatic diseases face a life-long battle resulting in serious joint damage, disability and possible death. By partnering with a rheumatologist to begin early treatment, patients are able to reduce the disability, deformity and costs associated with these diseases.
Our window of opportunity

You now know the problem: over 11 million Americans are living with the devastating effects of rheumatic diseases – suffering from chronic pain, organ damage, disability and death.

You also know the solution: rheumatologists – the rheumatic disease specialists who have experience and expertise in diagnosing, treating, managing and controlling these diseases.

Finally, you know there is a window of opportunity: the first weeks and months after symptom onset is the optimal time to start early and aggressive treatment. Appropriate and timely referrals, legislation guaranteeing access to rheumatologists, supporting research and initiatives to grow the rheumatology workforce, and understanding the importance of the practice of rheumatology are all crucial to ensuring more people with rheumatic diseases are treated within the window of opportunity.

What’s your window of opportunity?

Join the rheumatologist and rheumatology health professional members of the American College of Rheumatology and over 11 million Americans in fighting the devastating effects of rheumatic diseases.

If you are a LAWMAKER or ADMINISTRATION OFFICIAL, you can help by:

Educating yourself on the issues:

Learn how rheumatic diseases are affecting your constituents and how rheumatologists are helping them fight back. Rheumatologists and their patients are passionate and educated about the issues and are willing to share their knowledge with you.

Advancing rheumatology research:

Support increases in funding to federal programs engaged in vital research to combat arthritis and related diseases, including rheumatic diseases.

Championing rheumatology legislation:

Support legislation ensuring access to care for rheumatology patients and fair reimbursements for rheumatologists.

If you are a PHYSICIAN or a HEALTH PROFESSIONAL, you can help by:

Ensuring timely and appropriate referrals:

Establish a solid relationship with rheumatologists in your community. When a patient presents with an unusual case including inflammation and other signs and symptoms of a rheumatic disease, reach out to a rheumatologist to discuss the case and determine if a referral is appropriate. By ensuring timely and appropriate referrals, you will help your patients with rheumatic diseases start early and aggressive treatment within their window of opportunity.

Continuing to learn about rheumatic diseases:

Read the literature, attend conferences and invite a rheumatologist to speak to your medical association. By learning more about rheumatic diseases, you will be able to identify these complex diseases and you will know when it is necessary to reach out to a rheumatologist.

If you are an ADVOCATE FOR MEDICAL PROFESSIONALS OR PATIENTS, you can help by:

Educating your constituents on rheumatic diseases and the importance of rheumatology:

Ensure your constituents understand rheumatic diseases are devastating to those who suffer from them and to the health care system as a whole. Educate your constituents on the importance of rheumatology as the specialty devoted to treating these diseases.

Joining the American College of Rheumatology in lobbying on behalf of the rheumatology community:

Add your organization’s voice to the over 11 million Americans living with rheumatic diseases and to the thousands of rheumatologists and rheumatology health professionals who are promoting legislation to benefit their patients and to support their specialty.

For more information, visit www.SimpleTasks.org.