

From the Leading Authority on Arthritis & Related Diseases



Arthritis By The Numbers

Book of Trusted Facts & Figures

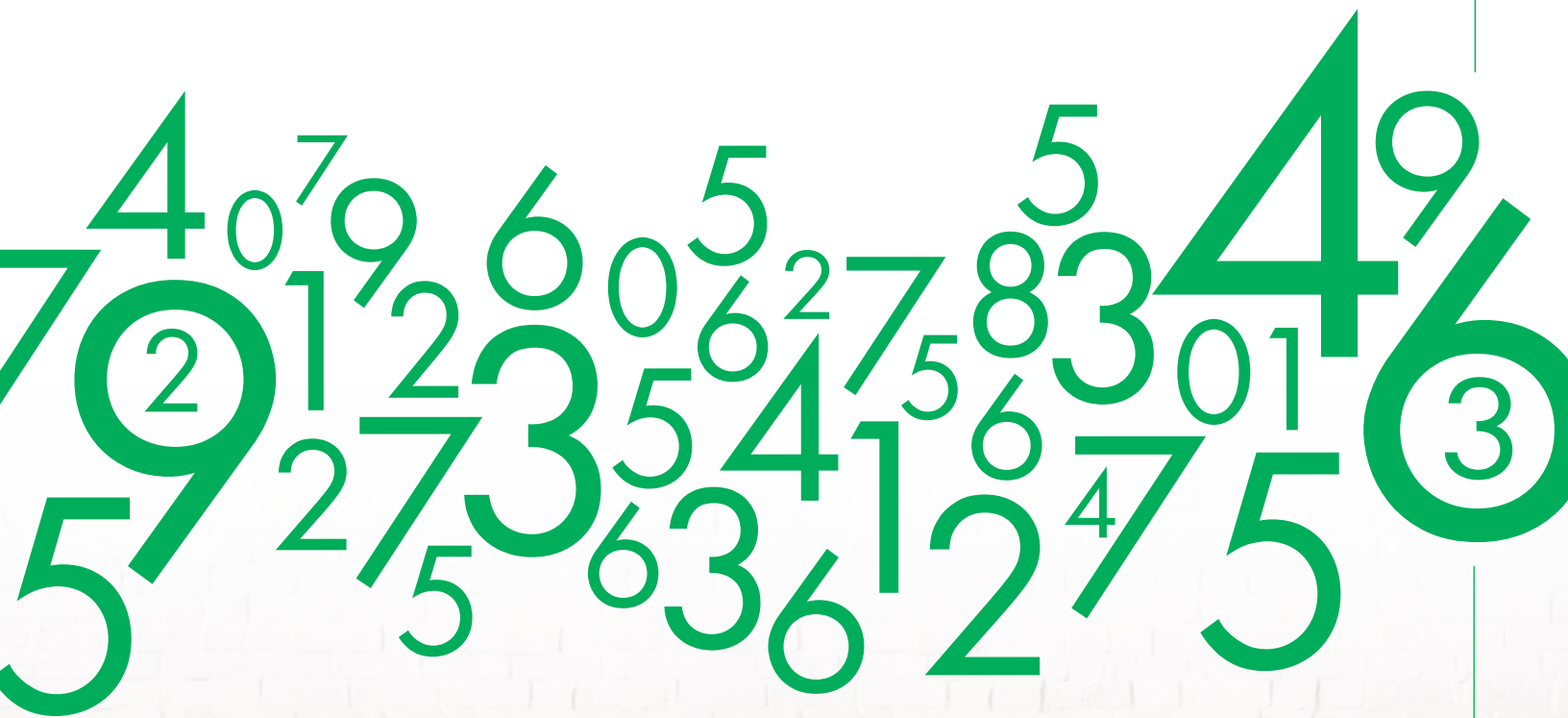


TABLE OF CONTENTS

Introduction	5
Section 1: General Arthritis Facts	7
o Human and Economic Burdens.....	9
- Economic Burdens.....	9
- Employment Impact and Medical Cost Burden.....	10
• Osteoporosis	12
o Prevalence	12
o Human and Economic Burdens.....	13
- Health Burdens.....	14
- Economic Burdens.....	14
Section 2: Osteoarthritis (OA).....	16
• # OA Patient Story – Kathy Geller.....	17
• Osteoarthritis (OA)	
o Prevalence	19
- US General Population	19
- Global Prevalence.....	19
o Human and Economic Burdens	20
- Health Burdens	20
- Knee, Hip and Shoulder OA Burden	21
- Economic Burdens	22
- Global Burden	23
o Military OA	26
- Prevalence in the Military	26
- Human and Economic Burden.....	26
- Global Burden for Military and Other Tactical Athletes.....	26
Section 3: Autoimmune and Inflammatory Arthritis	28
• # RA Patient Story – Eileen Schneider	30
• Rheumatoid Arthritis (RA)	31
o Prevalence	31
o Human and Economic Burdens	31
- Health Burdens	31
- Work/Employment Impact.....	32
- Medical/Cost Burdens	32
• # SLE Patient Story – Liz Morass.....	33
• Systemic Lupus Erythematosus (SLE or Lupus)	34
o Prevalence	34
o Human and Economic Burdens	35
- Comorbidities and Health Burdens	35
- Pregnancy Impact.....	37
- Work/Employment Impact.....	37
- Medical/Cost Burdens	38

• Sjögren’s Syndrome	40
o Prevalence (Primary Sjögren’s Syndrome)	40
o Comorbidities (Secondary Sjögren’s Syndrome).....	40
o Human and Economic Burdens	41
- Health Burdens	41
- Work/Employment Impact.....	45
- Medical/Cost Burdens	45
• Adult-onset Scleroderma	46
o Prevalence	46
o Human and Economic Burdens	46
- Health Burdens	46
- Economic Burdens	47
• Spondyloarthritis (SpA)	48
o General Prevalence	48
• Ankylosing Spondyloarthritis (AS)	48
o Prevalence	48
o Human and Economic Burdens	48
- Health Burdens.....	48
- Economic Burdens	49
• # PsA Patient Story – Karen Lomas	50
• Psoriatic Arthritis (PsA)	51
o Prevalence.....	51
o Human and Economic Burdens	51
- Health Burdens	51
- Economic Burdens	52
Section 4: Juvenile Idiopathic Arthritis (JIA)	
and Other Childhood Rheumatic Diseases	54
• Common Forms of Juvenile Arthritis (JA)	55
• # JIA/ Juvenile-onset Fibromyalgia Patient Story – Soler Family	56
• Juvenile Idiopathic Arthritis (JIA)	58
o Prevalence	58
o Human and Economic Burdens	59
- Health Burdens	59
- Mental Health Impact	60
- School and Social Impact.....	60
- Economic Burdens	60
• Juvenile-onset Systemic Lupus Erythematosus (SLE or Lupus)	63
o Prevalence	63
o Health Burdens.....	63

• Juvenile-onset Scleroderma	66
o Prevalence	66
o Health Burdens	66
• Juvenile Myositis (JM)	68
o Prevalence	68
o Health Burdens	68
• Juvenile-onset Fibromyalgia	70
o Prevalence	70
o Health Burdens	70
Section 5: Gout	73
• # Gout Patient Story – Craig Buhr	74
• Gout	
o Prevalence	75
o Human and Economic Burdens	75
- Health Burdens and Comorbidities	75
- Gout in Women	75
- Work/Employment Impact	76
- Medical/Cost Burden	76
Section 6: Fibromyalgia	78
• Fibromyalgia	
o Prevalence	80
o Human and Economic Burdens	80
- Disease Triggers	80
- Health Burdens	80
- Economic Burdens	81
o Juvenile-Onset Fibromyalgia	81
Conclusion	82
References	83
Appendix 1: Types of Arthritis	94
Appendix 2: Arthritis Foundation-Funded Research	95
Acknowledgements	102

INTRODUCTION

“I have stood on a mountain of Nos for one Yes!”

–B. Smith

“What you do speaks so loudly that I cannot hear what you say.”

–Ralph Waldo Emerson

The Arthritis Foundation launched the Live Yes! Arthritis NetworkSM in October 2018 – making connections possible, both in person and online, to empower people to live their best life. People with arthritis can find strength in each other, manage stress and take control of their health care through informed choices. We each make the choices of whether, how and where to connect. As individuals, we search for what’s right for each of us and to find our own, personal moments of Yes. Of accomplishing what we want to achieve..

It’s all about patients, researchers and health care providers – working together – to find answers that equip us to find new treatments and cures. We invite you to become part of the new Live Yes! Arthritis Network by visiting arthritis.org/LiveYes and taking part in local events, online forums and many other opportunities.

Last year we began to elevate the level of patient involvement in the creation of Arthritis by the Numbers. We believe patients must be fully integrated into everything we do, and that their diverse needs and outcomes, the ones that are most important to them, are represented. We continue to grow that involvement in this third edition of Arthritis by the Numbers by adding:

- New sections and updating older sections, while trying to find answers to questions that were important to patients
- Facts from the “Osteoarthritis Voice of the Patient” report and the “Lupus: Patient Voices” report, as well as Arthritis Foundation survey data collected from arthritis patients
- Patient reviewer stories, telling us how arthritis ... and the facts they reviewed ... relate to everyday life.

The 2019 edition of Arthritis by the Numbers includes three new sections – and about 200 new and/or updated observations about arthritis. It can be used by a wide audience as a trustworthy set of verified facts, meant to inform patients and patient advocacy thought-leaders, elected officials, academics, drug/device industry professionals, rheumatology health care providers, researchers and many others.

We’re more powerful together! By prioritizing policies that further advance the needs of people with arthritis, we can accelerate the science of finding better treatments and cures. We invite you to get started with us by flipping through the 2019 Arthritis by the Numbers.

“The power you have is to be the best version of yourself you can be, so you can create a better world.”

–Ashley Rickards



BY NEW ESTIMATES, 92.1
MILLION ADULTS HAVE
DOCTOR-DIAGNOSED
ARTHRITIS OR REPORT
ARTHRITIS SYMPTOMS.

(Jafarzadeh 2017)





Section 1:

General Arthritis Facts

What Is Arthritis?

Arthritis is very common but not well understood. Actually, “arthritis” is not a single disease; it is an informal way of referring to joint pain or joint disease. There are more than 100 different types of arthritis (see Appendix 1) and related conditions. People of all ages, genders and races can and do have arthritis, and it is the leading cause of disability in the United States. We don’t know the true number of people with arthritis because many people don’t seek treatment until their symptoms become severe. Conservative estimates only include patients who report they have doctor-diagnosed arthritis, indicating that more than 54 million adults and almost 300,000 children have arthritis or another type of rheumatic disease.

A recent study attempted to include patients who were doctor-diagnosed with arthritis, as well as people who reported joint symptoms consistent with a diagnosis of arthritis. These adjusted estimates indicate there are potentially more than 91 million adults in the U.S. living with arthritis. Another way of saying it: On the “ground floor” today, at least 54 million Americans suffer from arthritis; but the current “ceiling” may be almost twice that number. While researchers try to find more accurate ways to estimate the prevalence of this disease and the burdens it causes, we do know that it is most common among women, and the number of people of all ages with arthritis is increasing.

Common arthritis joint symptoms include swelling, pain, stiffness and decreased range of motion. Symptoms may come and go, and can be mild, moderate or severe. They may stay about the same for years and then may progress or get worse over time. Severe arthritis can result in chronic pain, inability to do daily activities and make it difficult to walk or climb stairs. Arthritis can cause permanent joint changes. These changes may be visible, such as knobby finger joints, but often the damage can only be seen by X-ray. Some types of arthritis also affect other body parts, like the heart, eyes, lungs, kidneys and skin.

The following facts describe some of the features common to many forms of arthritis.

General Facts

- There are more than 100 types of arthritis. (CDC 2016)

- Currently, arthritis affects more than one in four adults.

- In rural areas in the U.S, one in three adults has arthritis.

(Barbour – MMWR [66] 2017)

- Newer adjusted estimates for 2015 suggest that arthritis prevalence in the U.S. has been substantially underestimated, especially among adults younger than 65.

- Based on adjusted estimates, 92.1 million adults either have doctor-diagnosed arthritis and/or report joint symptoms consistent with a diagnosis of arthritis.

- For people aged 18 to 64, nearly one in three (both men and women) have doctor-diagnosed arthritis and/or report joint symptoms consistent with a diagnosis of arthritis.

- For those over 65, the numbers are much worse:

- o More than one in two men may have arthritis.

- o More than two in three women may have arthritis.

(Jafarzadeh 2017)

- Even though obesity has been recognized as a risk factor for arthritis, the prevalence of obese people with all types of arthritis decreased significantly between 1999 and 2014. (Park 2018)

- By conservative estimates, between 2002-2014, almost two-thirds (64 percent) of adults with doctor-diagnosed arthritis were younger than 65 years old. (Barbour -MMWR [65] 2016)

- By conservative estimates, between 2010-2012:

- Almost 50 percent of adults 65 or older reported doctor-diagnosed arthritis.

- Arthritis was more common among women (26 percent) than men (19 percent).

- About 4 million Hispanic adults had doctor-diagnosed arthritis.

- About 6 million non-Hispanic blacks had doctor-diagnosed arthritis.

- Arthritis was more common among adults who are obese than among those who are normal weight or underweight.

(Barbour 2013)

- By conservative estimates, between –2013-2015:

- About 54.4 million adults in the U.S. (22.7 percent of all adults) had doctor-diagnosed arthritis.

- o 23.7 million (43.5 percent of those with arthritis) reported activity limitations due to their arthritis.

- o There was an increase of about 20 percent in the number of adults with arthritis who reported activity limitations since 2002.

(Barbour – MMWR [66] 2017)

- By conservative estimates, by 2040:

- The number of adults in the U.S. with doctor-diagnosed arthritis is projected to increase 49 percent to 78.4 million (25.9 percent of all adults).

- The number of adults reporting activity limitations due to their arthritis will increase 52 percent to 34.6 million (11.4 percent of all adults). (Hootman 2016)

- Lumbar spine osteoarthritis (OA) is very common. Between 40 to 85 percent of people with chronic low back pain (LBP) may have it.

- About 80 percent of Americans experience LBP at least once during their lives, making it the second most common condition after the common cold in frequency.

- LBP affects more than 30 percent of the adult U.S. population in a given year and is one of the most common reasons for doctor visits. (Goode 2013)

By new estimates,

1 in 3
people age
18-64 have
arthritis.



(Jafarzadeh 2017)

Human and Economic Burdens

Health Burdens

- Only 7 percent of all rheumatologists practice in rural areas, where 20 percent of the population lives. (ACR 2013)
- Arthritis is the most common chronic condition among chronic users of opioids in the U.S. (Hudson 2008)
- In 2014, more than one in four adults with arthritis had severe joint pain (27 percent).
 - Among adults with arthritis, the highest prevalence of adults with severe joint pain was among persons 45 to 64 years old (31 percent). (Barbour -MMWR [65] 2016)
- Severe joint pain was higher among women (29 percent) and those who:
 - Had fair or poor health (49 percent)
 - Were obese (32 percent)
 - Had heart disease (34 percent)
 - Had diabetes (41 percent)
 - Had serious psychological distress (56 percent)
 (Barbour -MMWR [65] 2016)
- The prevalence of severe joint pain among adults with arthritis was stable from 2002 to 2014, but the absolute number of adults with severe joint pain was significantly higher in 2014 (14.6 million) than in 2002 (10.5 million), due in part to population growth. (Barbour -MMWR [65] 2016)

Arthritis is the most common chronic condition among chronic users of **opioids** in the U.S.



(Hudson 2008)

- Physical activity can reduce pain and improve physical function by about 40 percent. (Barbour - MMWR [66] 2017)
- Between 2008 and 2015, fewer people with arthritis met aerobic and muscle strengthening guidelines than people without arthritis.
 - People with arthritis may need additional strategies to address potential barriers to physical activity – such barriers as pain, psychological distress and inadequate medical support. (Murphy 2017)
- Almost half of all adults with heart disease (49.3 percent) also have arthritis.
 - More than half (54.5 percent) of adults with arthritis and heart disease have activity limitations. (Barbour - MMWR [66] 2017)
- Almost half of all adults with diabetes (47.1 percent) also have arthritis.
 - More than half (54 percent) of adults with arthritis and diabetes have activity limitations. (Barbour - MMWR [66] 2017)
- Almost one-third (30.6 percent) of all adults who are obese also have arthritis.
 - About half (49 percent) of adults with arthritis who are also obese have activity limitations. (Barbour - MMWR [66] 2017)
- Obesity affects 36.5 percent of all adults in the U.S. and occurs frequently among those with arthritis. Those with obesity and arthritis are more likely to:
 - Have arthritis activity and work limitations
 - Be physically inactive
 - Report depression and anxiety
 - Have an increased risk of expensive knee replacement (Barbour 2016)
- From 2009 to 2014, an increase in obesity prevalence in older adults with doctor-diagnosed arthritis occurred among those with poor health characteristics, as might be expected. An increase in obesity prevalence also occurred among those who reported meeting physical activity recommendations, those with very good/excellent health and those without heart disease, diabetes or serious psychological distress. (Barbour 2016)

- In the U.S., about one in three adults with arthritis, 45 years and older, report having anxiety or depression. *(Murphy 2012)*
- Anxiety is nearly twice as common as depression among people with arthritis, despite more clinical focus on the latter mental health condition. *(Murphy 2012)*
- Among people with arthritis:
 - Nearly one in four adults also has heart disease.
 - 19 percent also have chronic respiratory conditions.
 - 16 percent also have diabetes.
 - It is believed that arthritis likely comes first and results in these other health problems.*(Murphy 2009)*
- Arthritis is strongly associated with major depression (attributable risk of 18.1 percent), probably through its role in creating functional limitation. *(Dunlop 2004)*
- While back pain is common, the cause is often unclear and classification is controversial:
 - Most back pain probably starts in the muscles and/or ligaments;
 - Or it's caused by degenerative changes in the spine itself (the vertebrae and the discs that separate them).*(Lawrence 2008)*

- About 15 to 21 percent of the adult population in the U.S. reports frequent low back pain.
 - About 14 percent report low back pain lasting longer than two weeks at a time.
 - About 5 to 10 percent of patients have low back pain lasting more than three to six months.
 - About 1 to 2 percent of adult patients have been diagnosed with herniated discs.*(Lawrence 2008)*
- There are several forms of arthritis that can affect the back, including:
 - ankylosing spondylitis
 - psoriatic arthritis
 - osteoarthritis
 - rheumatoid arthritis
 - gout
 - fibromyalgia
 - osteoporosis
 - spinal stenosis
 - sciatica
 - scoliosis*(AF 2018)*

Employment Impact and Medical Cost Burden

- Arthritis is the leading cause of disability among adults in the U.S. *(Barbour 2013)*
- Stroke is often considered the most common cause of disability, but both arthritis and back pain probably have a greater impact on functional limitations than stroke. *(Ma 2014)*
- Back pain is a leading cause of work disability. *(Lawrence 2008)*
- Back pain and arthritis (osteoarthritis and rheumatoid arthritis) are the most common and costly conditions requiring rehabilitation in the U.S.
 - Back pain and arthritis affect more than 100 million people and cost over \$200 billion per year. *(Ma 2014)*
- Musculoskeletal conditions like back pain and arthritis are likely to have the greatest impact on the health care system because of their high prevalence and the level of disability they cause. *(Ma 2014)*

Arthritis is the
**Leading Cause
of Disability**
among adults in
the U.S.



(Barbour 2013)



- Annually, 172 million work days are lost due to arthritis and other rheumatic conditions. (BMUS 2014)
- In 2013, fewer adults with arthritis (77 percent) were able to work compared to adults without the disease (84 percent). (Murphy 2017)
- In 2013, total medical costs and earning losses due to arthritis were \$304 billion (about 1 percent of the U.S. gross domestic product for 2013).
 - Total earning losses were higher than medical costs. (Murphy 2017)
- In 2013, earning losses were \$164 billion (for adults with arthritis between ages 18 and 65).
 - The average adult with arthritis earned \$4,040 less than an adult without arthritis. (Murphy 2017)
- In the U.S. in 2013, adults spent about \$140 billion on medical costs related to arthritis, affecting 66 million people.
 - The average medical costs per person with arthritis were \$2,117. (Murphy 2017)
- Health care services worldwide will face severe financial pressures in the next 10 to 20 years due to the increase in the number of people affected by musculoskeletal diseases.
 - By the year 2040, the number of individuals in the United States older than 65 is projected to grow from the current 15 percent of the population to 21 percent.
 - Those 85 and older will double from the current, from less than 2 percent to 4 percent. (BMUS 2014)
- In 2010, there were more than 100 million outpatient visits due to arthritis (nearly 10 percent of all visits that year). (BMUS 2014)
- In 2011, there were an estimated 6.7 million hospitalizations due to arthritis (17.3 percent of all hospitalizations that year). (BMUS 2014)
- In 2010 and 2011, there were an estimated 706,000 to 757,000 knee replacement procedures performed in the U.S.
 - In 2010 and 2011, there were an estimated 465,000 to 512,000 hip replacement procedures. (BMUS 2014)

MORE THAN 17 PERCENT OF
ALL HOSPITALIZATIONS IN
2011 WERE DUE TO ARTHRITIS.

(BMUS 2014)

Osteoporosis

Bones are living tissue made of calcium and other minerals. Bone tissue is replaced regularly in a process called bone turnover.

Osteoporosis means “porous bone.” It is a disease that occurs when your body loses too much bone, makes too little bone, or both. The bones become thinner and brittle (less dense) and are more likely to break (or fracture) with pressure or after a fall. Bone loss happens without any warning signs. That’s why osteoporosis is called a “silent disease.”

From childhood into young adulthood, the body produces more than enough cells to replace those that die, resulting in stronger, denser bones. By age 30, bones are at peak bone density, and cell turnover remains stable for several years in most people. A slow decline in bone mineral density (BMD) occurs when bone cells start to die at a more rapid rate than new cells are produced. This may lead to the development of osteopenia (a less severe form of bone density loss) and osteoporosis.

Any bone in the body can be affected by osteoporosis. However, the spine, hips, ribs and wrists are the most commonly fractured when a person with osteoporosis falls. Osteoporosis can also cause a hump in the upper back or loss of height.

Who’s Affected?

Osteoporosis is more common in women. It is the main cause of bone fractures in postmenopausal women and the elderly. However, men can also get osteoporosis. While osteoporosis is more common in people 50 and older, it can occur in younger people, too.

Risk factors for developing osteoporosis include family history, gender, race, weight, diet and exercise. Risk factors for low BMD in younger (pre-menopausal) women include low body weight, amenorrhea, lack of physical activity, smoking, low dietary calcium or vitamin D, pregnancy and being of the Caucasian or Asian race. Of the pre-menopausal women who develop this disease, it is thought that 50 to 90 percent have a secondary cause. Secondary causes can include drugs (like glucocorticoids, anticonvulsants, heparin and alcohol), endocrine diseases (like growth hormone deficiency and Type 1 diabetes), malnutrition or malabsorption diseases (like anorexia, inflammatory intestinal disease and celiac disease), inflammatory diseases (like rheumatoid arthritis and lupus), organ and bone marrow transplants, and other causes. (McLendon 2014)

For osteoporosis prevention, it is recommended that women ages 18 to 50 consume 1,000 mg of calcium and 600 IU of vitamin D daily, as well as perform regular weight-bearing exercises, avoid smoking and alcohol, and limit caffeine consumption. (McLendon 2014)

Prevalence

- One in two women over age 50 will break a bone in their lifetime due to osteoporosis.
 - For women, the chance of developing osteoporosis is greater than that of heart attack, stroke and breast cancer combined. (NOF 2015)
- Up to one in four men over 50 will break a bone in their lifetime due to osteoporosis.
 - A man is more likely to break a bone from osteoporosis than to get prostate cancer. (NOF 2015)
- Osteoporosis and low bone mass combined affected more than half (53.6 million) of older adults (age 50 and above) in 2010.
 - 10.2 million adults had osteoporosis
 - 43.4 million had low bone mass (Wright 2014)

Globally, more than 200 million women suffer from osteoporosis.

- One in three postmenopausal women have this disease in the U.S. and Europe.
- Worldwide, osteoporosis in women increases with age:
 - o One in 10 women at age 60
 - o One in five women at age 70
 - o Two in five women at age 80
 - o Two in three women at age 90
- Aging populations will be responsible for a major increase in the global number of people with this disease.

(IOF Facts 2018)



Prevention

- Many younger postmenopausal women (in their 50s and 60s) often mistakenly categorize osteoporosis as a largely unavoidable part of aging. A recent survey of postmenopausal women indicated the following incorrect assumptions about this disease:

- Three in 10 women believe that drinking milk or taking calcium supplements alone will prevent osteoporosis.
- One in four believe there is no way to build new bone at their age.
- Three in 10 women with osteoporosis believe the risk of a bone fracture or break cannot be reduced in women their age. (NOF 2017)

- Due to limited recognition and discussion about the link between osteoporosis and fracture, only two in 10 older women in the U.S. who suffer a fracture are tested or treated for osteoporosis.

- About 96 percent of postmenopausal women who have not been diagnosed with osteoporosis and have had a fracture or break from falling were not told by their doctor that it could be linked to osteoporosis. (NOF 2017)

- Bone density tests can help spot bone loss in people who might have no symptoms.

- The test is painless, quick and safe, and can alert people to bone loss before a fracture occurs.
- The test can track the effects of medicines used to manage bone disease. (Yu 2018)

- The lower the bone density, the greater the risk of having a fracture. To reduce the chances of breaking a bone and improve bone density, patients can combine the following:

- Take osteoporosis medicines as prescribed by a doctor.
- Improve diet and take calcium with vitamin D supplements.
- Take part in an exercise program that improves muscle strength and includes weight-bearing exercises. (Yu 2018)

- Tai chi chuan (tai chi), an ancient form of slow and relaxed exercise, has been shown to be beneficial to bone mineral density (BMD) and may help prevent osteoporosis. Tai chi practice:

- Is time-dependent – a longer period of practice is required to improve BMD
- Is beneficial toward balance and coordination
- Can improve physical performance and reduce fear of falling (Chow 2018)

- A 10-year study with women showed that 12 selected yoga poses appear to be a safe and effective means of reversing bone loss in the spine and femur (upper leg bone).

- The women practiced the yoga routine at least every other day for two years.
- The average age when women started the yoga practice was 68.
- About 83 percent of the women had lower-than-normal bone density at the start.
- By the end of the study, most showed significant increases in bone density in the spine.
- No bone fractures or other injuries were caused by doing yoga.
- There may also be some benefit to hip bone density.

(Lu 2016)

**BONE DENSITY
TESTS CAN HELP
SPOT BONE LOSS
IN PEOPLE WHO
MIGHT HAVE NO
SYMPTOMS.**

(Yu 2018)

Health Burdens

- Osteoporosis leads to about 2 million fractures a year in the U.S., including:
 - 550,000 spinal (vertebral) fractures
 - 300,000 hip fractures
 - 400,000 wrist fractures
 - 810,000 other body part fractures *(Burge 2006)*
- Vertebral fractures are the most common fractures caused by osteoporosis.
 - They are the gateway to more serious and expensive fractures, like hip fractures. *(Ensrud 2013)*
- Once a person has a hip fracture, they are more likely to suffer additional fractures. *(Cauley 2013)*
- People with osteoporosis can break a bone from a minor fall, or even from sneezing or bumping into furniture. *(NOF 2015)*
- Half of all adults over age 50 are at risk of breaking a bone due to this disease.
 - One in four hip-fracture patients over 50 die within a year of the fracture.
 - Only 15 percent of patients can walk across a room unaided after a hip fracture.
 - One in four patients ends up in a nursing home.
 - Half never regain previous function. *(NOF 2015)*
- Women account for 71 percent of all fractures and 75 percent of all fracture-related costs. *(Cauley 2013)*
- Among women with disease-related fractures:
 - 89 percent are white.
 - 4 percent are African American.
 - 4 percent are Hispanic.
 - 3 percent are from other races/ethnicities. *(Cauley 2013)*
- While fractures related to this disease are more common in women, studies have shown that the fracture-related death rate is higher in men. *(Burge 2007)*
- Almost a third of the fractures and a quarter of the total cost burden of disease-related fractures is borne by men. *(Burge 2007)*

- Over the next 20 years, the total number of osteoporosis fractures and related costs will increase for the nonwhite population.
 - A 2.7-fold increase in the number of fractures and costs for Hispanic and other racial/ethnic populations is predicted by 2025. *(Burge 2007)*
- Worldwide, osteoporosis causes at least 8.9 million fracture a year (one fracture every three seconds). For people over age 50:
 - One in three women will have osteoporotic fractures.
 - One in five men will have osteoporotic fractures. *(IOF 2018)*
- Globally, at least half of the hip fractures due to this disease will occur in Asia by 2050. *(IOF 2018)*

Economic Burdens

- In 2006, annual direct costs to Medicare patients with fractures was more than 1.5 times higher than patients without fractures. *(Cauley 2013)*
- In 2008, direct care costs during the first post-fracture year were about:
 - \$8,000 for vertebral (back bone) fractures
 - \$11,300 for nonvertebral fractures
 - \$30,000 for hip fractures *(Tosteson 2008)*
- In the U.S. in 2015, broken bones from this disease cost patients and the health care system \$19 billion a year. *(NOF 2015)*
- By 2025, it is predicted that this disease will cause 3 million fractures and costs will exceed \$25 billion a year in the U.S. *(NOF 2015)*
- Globally:
 - Forty percent of osteoporotic fractures occur in people of working age.
 - The direct annual cost of treating osteoporotic fractures of people in the workplace is \$48 billion in Canada, Europe and the U.S.
 - o This does not take into account indirect costs, such as disability and loss of productivity. *(IOF Factsheet 2014)*



IN 2013, TOTAL MEDICAL
COSTS AND EARNINGS
LOSSES DUE TO ARTHRITIS
WERE \$304 BILLION

(MURPHY 2017)



Section 2:

Osteoarthritis

What is Osteoarthritis?

Osteoarthritis (OA) isn't just a disease that affects old people. It's the most common form of arthritis, affecting more than 30 million Americans, of whom more than half are under age 65. Anyone who injures or overuses their joints, including athletes, military members and people who work physically-demanding jobs, may be more susceptible to developing this disease as they age. OA is a chronic condition that can affect any joint, but it occurs most often in the knees, hips, lower back and neck, small joints of the fingers and the bases of the thumb and big toe. Currently, there is no cure for OA.

In normal joints, cartilage covers the end of each bone. Cartilage provides a smooth, gliding surface for joint motion and acts as a cushion between the bones. In OA, the cartilage breaks down, causing pain, swelling and problems moving the joint. As OA worsens over time, bones may break down and develop growths called spurs. Bits of bone or cartilage may chip off and float around in the joint. This can cause inflammation and further damage the cartilage. In the final stages of OA, the cartilage wears away and bone rubs against bone, leading to joint damage and more pain. When OA becomes severe, other than treating symptoms with pain medications, the only option for treatment becomes joint replacement.

Despite the challenges of this disease, OA patients remain optimistic. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 92 percent of those patients say there are lots of ways around any problem.

The following facts describe some of the features common to OA.



Rethinking Life With Severe Osteoarthritis

Meet Kathy Geller, who touched many lives during the years she spent as an Arthritis Foundation exercise trainer and education program presenter – a role model for successful self-management. Following, in her own words, is Kathy's story about living with severe degenerative osteoarthritis (OA) and how the statistics she reviewed in *Arthritis by the Numbers* relate to her personally.



Question: What changes has your osteoarthritis made to the way you live?

Kathy: During my 18-year struggle with severe OA, I wasn't always a Champion of Yes. Yes, I helped others battling arthritis. But inwardly, I was overwhelmed by all the "Nos" arthritis brought my way. No – I couldn't hold my first grandchild because my hands were in casts after joint replacement. No – I had to give up my profession because I could no longer assist clients or lift the equipment necessary to train them. No – I couldn't stay in the family home my husband and I built because it was too difficult for me after the 10+ OA surgeries I've endured, most recently to fuse two-thirds of my lumbar spine.

To say the quality of my life has been affected would be an understatement. My home environment consists of one-floor living. I have every imaginable arthritis-friendly utensil, jar opener, lightweight serving dishes and more. I think twice before traveling: How far will I have to walk through the terminal? Do I need to check my bag rather than lift it into an overhead bin? I must conserve my energy and pace my day.

"Giving in" should not be confused with "giving up." I finally accepted I am living with a chronic disease. OA is not life-threatening, but it's insidious. It slowly chips away at your cartilage and your spirit. With the help of the Arthritis Foundation, I've begun to turn those "Nos" into "Yeses." I have found my voice through the Foundation's Ambassador program.

Question: What advice would you give to a newly-diagnosed patient or parent/caregiver?

Kathy: My advice is to make sure you are seeing the right physician. This is a relationship you will have for a long time. It's crucial you feel a connection that enables you to open communication and develop a partnership. Find out all you can about the type of arthritis you have. Learn and practice as many self-management skills you possibly can: keeping body weight under control, staying active, exercising, pacing yourself. Don't be afraid to ask for help.

Arthritis has a significant effect on my life, but it doesn't define me. I appreciate the quiet times not filled with surgeries, recovery and therapy. And I know I'm strong and prepared to confront the active times when OA strikes again.





IN THE U.S., ABOUT 65 PERCENT OF PATIENTS WITH OA ARE PRESCRIBED NONSTEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDS), MAKING THEM ONE OF THE MOST WIDELY USED DRUGS IN THIS PATIENT POPULATION.

(Gore 2012)





Prevalence

U.S. General Population

- Today an estimated 30.8 million adults have osteoarthritis.

(Cisternas 2015)

- Osteoarthritis (OA) is the most common cause of disability in adults. (Lawrence 2008)

- In the athlete or young individual, injury, occupational activities and obesity are the main factors that contribute to the development of OA.

- Diagnosis of OA in the athlete is often delayed and difficult because of their high tolerance of pain, as well as the athlete's preference for expedited return to play. (Amoako 2014)

- Among people younger than 45, OA is more prevalent among men; among those 45 and older, it is more prevalent among women. (Berger 2011)

- The lifetime risk of developing symptomatic knee OA is 45 percent. (Murphy 2008)

- The prevalence of symptomatic knee OA:

- Increases with each decade of life, with the annual incidence of knee OA being highest between 55 and 64 years old
- Has been increasing over the past several decades in the U.S., concurrent with an aging population and the growing obesity epidemic (Deshpande 2016)

- There are 14 million individuals in the U.S. who have symptomatic knee OA.

- Nearly 2 million people under age 45 have symptomatic knee OA.
- The overall number of people in the U.S. with symptomatic knee OA is nearly identical between those 45 to 64 years old and those 65 or older (about 6 million in each age group).
- About one in five people who have symptomatic knee OA identify as a racial/ethnic minority, and that number is expected to rise. (Deshpande 2016)

- The prevalence of symptomatic knee OA in patients 45 and older has been estimated between:

- 5.9 and 13.5 percent in men
- 7.2 and 18.7 percent in women (AAOS 2013)

- In those 55 and younger, the prevalence of knee OA in men is lower compared to women. (Heidari 2011)

- About 13 percent of women and 10 percent of men 60 and older have symptomatic knee OA. (Zhang 2010)

- More than half of all individuals with diagnosed symptomatic knee OA have had sufficient progression of the disease that would make them eligible for knee replacement. (Deshpande 2016)

- More than half of all people with symptomatic knee OA are younger than 65 and will live for three decades or more after diagnosis. For these people, there is substantially more time for greater disability to occur. (Deshpande 2016)

- About 40 percent of adults in the U.S. are likely to develop symptomatic OA in at least one hand by age 85. (Qin 2017)

- The risk of developing symptomatic hand OA by age 85 differs across sexes, races and body mass index.

- Women are nearly twice as likely as men to develop it (47 percent versus 25 percent).
- Caucasians are more likely to develop it than African-Americans (41 percent versus 29 percent).
- Obese people are at greater risk than nonobese people (47 percent versus 36 percent). (Qin 2017)

- The lifetime risk is of developing symptomatic hip OA is 25 percent. (Murphy 2008)

Global Prevalence

- Osteoarthritis ranks fifth among all forms of disability worldwide. (Murray 2012)

- Osteoarthritis (OA) is the most common articular disease of the developed world and a leading cause of chronic disability, mostly because of knee OA and/or hip OA. (Grazio 2009)

- OA is thought to be the most prevalent of all musculoskeletal pathologies, affecting an estimated 10 percent of the world's population over the age of 60. *(Pereira 2011)*
- The prevalence of OA increases with age, up to 80 percent in people over age 65 in high-income countries. *(Fernandes 2013)*
- As the world's population continues to age, it's estimated that degenerative joint disease disorders such as OA will impact at least 130 million individuals around the globe by the year 2050. *(Maiese 2016)*
- At least 15 percent of all adults over age 60 are believed to suffer from OA.
 - Women are almost twice as likely to have OA than men.
 - 18.0 percent of women over age 60 suffer from OA.
 - 9.6 percent of men over 60 suffer from OA. *(Maiese 2016)*
- Adolescents and young adults with anterior cruciate ligament (ACL) injuries are prone to develop OA before they reach age 40. *(Oiestad 2010)*
- Knee injuries remain the most prevalent worldwide, with 700 000 cases annually in the U.S. and accounting for 12.5 percent of post-traumatic OA cases. *(Gage 2012)*
- Hip and knee OA represent a substantial cause of disability worldwide and are responsible for approximately 17 million years lived with disability globally. *(Cross 2014)*

Human and Economic Burdens

Health Burdens

- Advanced age, obesity, genetics, gender, bone density, trauma and a poor level of physical activity can lead to the onset and progression of osteoarthritis (OA). *(Gabay 2016)*
- Current therapies, including pain management, improved nutrition and regular programs for exercise, do not lead to the resolution of OA. *(Maiese 2016)*
- OA is linked to increased rates of comorbidity (e.g., obesity, diabetes and heart disease). *(Suri 2012)*

- In the U.S., about 65 percent of patients with OA are prescribed nonsteroidal anti-inflammatory drugs (NSAIDs), making them one of the most widely used drugs in this patient population. *(Gore 2012)*
- Women, particularly those 55 and older, tend to have more severe OA in the knee but not in other sites. *(Srikanth 2005)*
- Five common athletic injuries have been identified as placing patients at greater risk of developing post-traumatic OA:
 - anterior cruciate ligament (ACL) ruptures
 - meniscus tears (the second most common structure damaged in athletes)
 - shoulder dislocation
 - patellar dislocation
 - ankle instability (the most commonly injured joint in the body) *(Whittaker 2015)*
- A greater proportion of individuals with OA are reported to have depression (12.4 percent), as compared to individuals without the disease. *(Gore 2011)*
- Patients rate pain and tenderness as the symptoms that have the most impact on their daily lives. *(OA VOP 2017)*

Women, over the
age of 60, are almost
**twice as
likely** to have
OA than men

(Maiese 2016)



Many people with **OA** say the **pain, fatigue, disfigurement and mobility limitations** of the disease lead to social isolation.



(OA VOP 2017)

- After pain, stiffness was identified as a significant symptom that impacted daily life. Other impactful symptoms included:
 - functional, walking and standing limitations
 - loss of flexibility
 - sleep disturbance
 - fatigue
 - grating (bone on bone) sensation
 - joint swelling
 - disfigurement
 - other numbness and instability (OA VOP 2017)
- Friends, family and co-workers may not understand the impact of osteoarthritis that can be largely invisible.
 - OA causes an emotional toll because others don't understand the changing limitations of the disease.
 - Co-workers may assume their colleagues are getting special treatment with modifications, and the patient may feel ostracized for requiring the changes.
 - A significant amount of time and energy is required to continually manage daily symptoms, including advanced planning for treatments and other daily activities, and taking vacations. (OA VOP 2017)
- Many people with OA say the pain, fatigue, disfigurement and mobility limitations of the disease lead to social isolation, which impacts all their relationships.
 - Pain and physical limitations are a source of shame and embarrassment for many. (OA VOP 2017)

Knee, Hip and Shoulder OA Burden

- With the lifetime risk of symptomatic hip osteoarthritis (OA) estimated at 25.3 percent, conditions that can lead to OA must be addressed to reduce the quality of life lost, caused by disability and functional limitations, and their corresponding economic impact. (Murphy 2010)
- Knee OA is frequently accompanied by comorbidities that contribute to decreased quality of life:
 - obesity or being overweight (90 percent)
 - hypertension (40 percent)
 - depression (30 percent)
 - diabetes (15 percent) (Hunter 2011)
- Opioids do not appear to be cost-effective in OA patients without comorbidities, principally because of their negative impact on pain relief after total knee arthroplasty. (Rose 2016)
- The most severe fracture that can result from OA involves the hip, which requires hospitalization and leads to permanent disability in 50 percent of individuals and fatality in another 20 percent. (Maiese 2016)
- Although many patients eventually require total knee arthroplasty, they spend an average of 13 years exhausting pain-relieving drugs before undergoing surgery. (Losina 2015)
- From 1999 to 2008, the utilization rate of total knee replacement procedures in the U.S. more than doubled for the overall population and tripled for individuals age 45 to 64. (Losina 2012)
- It's estimated that 54 percent of knee OA patients will receive total knee replacement over their lifetime under current guidelines; the current trend suggests there may be a 29 percent increase in lifetime direct medical costs attributable to this procedure among knee OA patients. (Losina 2015)
- By the end stages of osteoarthritis, total knee arthroplasty is often necessary to address the degradation of the joint and the associated symptoms that severely limit day-to-day function. (Hochberg 2012)
- Coupled with increasing knee OA prevalence, the rising costs of health care may inflict a tremendous economic burden on society in the future. There are currently no medical or surgical treatments that will improve this alarming trajectory. (London 2011)

- More than 55,000 revision surgeries were performed in 2010 in the U.S., with 48 percent of them in patients under age 65.
 - Risks of revision surgery are especially pronounced in the younger patient, who may be more physically active and, consequently, subject to multiple revision surgeries over a lifetime. *(Bhandari 2012)*
 - In anterior cruciate ligament (ACL) ruptures, approximately 50 percent of those affected develop post-traumatic OA five to 15 years after injury (treated and with surgery). *(Whittaker 2015)*
 - By 2030, nearly two in three total knee arthroplasty revision patients will be under 65 years old. *(Kurtz 2009)*
 - More than 719,000 total knee arthroplasties were performed in 2010 in the U.S. *(HCUP 2010)*
- By 2012, surgery for end-stage knee OA was performed on 658,000 Americans annually. *(Bhandari 2012)*
- Hip and knee OA cause the greatest burden in terms of pain, stiffness and disability, leading to the need for prosthetic joint replacement in the most severe cases. *(Litwic 2013)*
- Between July 2007, and June 2012, people without significant comorbid conditions who underwent knee or hip replacement procedure had a greater decrease in OA-related health care resource utilization and costs after they recovered from surgery. *(Pasquale 2015)*
- Total hip arthroplasty is a highly successful medical intervention, having favorable long-term outcomes in improvement of physical functioning, survivorship and self-reported quality of life. *(Babovic 2013)*
- Across all patients, primary total hip arthroplasty is projected to grow by 75 percent between 2010 and 2020. *(Kurtz 2014)*
- The number of total hip arthroplasties performed on patients 18 to 64 years old increased by 91 percent between 2003 and 2013. *(HCUP 2015)*
- One study projected that more than 50 percent of total hip arthroplasties will be performed in patients younger than 65 by 2030. *(Kurtz 2009)*
- Infection is a devastating complication after shoulder arthroscopy or arthroplasty, which can lead to substantial morbidity. Recent studies have reported a rate of infection of 0.27 percent after shoulder arthroscopies and up to 15 percent of shoulder arthroplasties. *(Werner 2016)*
- Most shoulder prosthetic infections are diagnosed after patients are discharged. *(Poulosides 2012)*
- The 90-day readmission rate for shoulder arthroplasty has been reported to be as high as 6 percent; these rates have been reported to be increasing. *(Matsen 2015)*
- The rate of revision for failed shoulder arthroplasty per 100,000 population has grown by 400 percent over the last two decades; revisions have been reported to account for up to 10 percent of all shoulder arthroplasties. *(Matsen 2015)*
- Factors associated with the risks of longer lengths of hospital stay, readmission within 90 days and revision surgery:
 - Advancing age was associated with longer lengths of stay and more frequent readmission, but with fewer surgical revisions.
 - Women, African-Americans and Medicaid patients had longer lengths of stay.
 - Patients who underwent arthroplasty for fracture-related problems had longer lengths of stay.
 - Patients who underwent arthroplasty for traumatic arthritis and osteoarthritis had shorter lengths of stay but more revision surgeries.
 - Facilities with the highest-case volumes had longer lengths of stay and higher 90-day readmission rates. *(Matsen 2015)*

Economic Burdens

- Costs of short-term disability, workers' compensation and absenteeism are much higher among persons with osteoarthritis (OA). *(Berger 2011)*
- Earning losses due to OA cost an estimated \$80 billion per year between 2008 and 2011. *(OAA 2014)*

Knee osteoarthritis contributes more than \$27 billion in health care expenditures annually.

(Losina 2015)



- A study in 2012 demonstrated that OA was the highest cause of work loss and affected more than 20 million individuals, costing the U.S. economy more than \$100 billion annually. (Sandell 2012)
- It has been estimated that the costs due to absenteeism from OA alone are at least \$11.6 billion due to an estimated three lost workdays per year. (Kotlarz 2010)
- Employed individuals with evidence of osteoarthritis have much higher health care costs over a single year than those of similar age and gender without evidence of OA. (Berger 2011)
- OA consumes a tremendous amount of medical resources and causes considerable disability. (Rivera 2012)
- OA accounts for more than 25 percent of all arthritis-related health care visits. (AAOS 2008)
- During fiscal year 2011, the Medicare program reimbursed U.S. hospitals:
 - \$3.5 billion for total knee arthroplasty (the program's largest expenditure for a single procedure)
 - \$3.4 billion for heart failure
 - \$2.0 billion for coronary intervention with drug-eluting stents
 - \$3.2 billion for spinal fusion (Culler 2015)

- Over 1 million total joint arthroplasties, at a cost of \$18.8 billion, were performed in the United States in 2012.

(CDC-Table 105 2015)

- By 2013, knee OA contributed to more than \$27 billion in health care expenditures annually. (Losina 2015)
- In 2010, each total knee arthroplasty revision surgery was associated with total costs of \$49,360. (Bozic 2010)
- In 2013, each primary total knee arthroplasty (TKA) cost an average of \$20,293, and each revision TKA cost an average of \$26,388. (Losina 2015)

- Compared with nonsurgical treatments, total hip arthroplasty increased average annual productivity of patients by \$9,503. (Koenig 2016)

- The total lifetime societal savings for hip repair or replacement were estimated at almost \$10 billion from more than 300,000 procedures performed in the U.S. each year. (Koenig 2016)

- Hip OA profoundly affects quality of life in the U.S., with estimated costs as high as \$42.3 billion from 904,900 hip and knee replacements in 2009. (Murphy 2012)

- A recent study found infection was the most common surgical cause of readmission after shoulder arthroplasty and that these readmissions incurred an average hospital cost of \$11,000. (Schairer 2014)

Global Burden

- In developed nations, osteoarthritis (OA) is one of the 10 most common disabilities in older individuals, especially those who remain active in the workforce. (Palmer 2015)
- The total number of years lived with disability worldwide caused by knee and hip OA increased by 60.2 percent between 1990 and 2010, and by 26.2 percent per 1,000 people. This means OA has moved up, from 15th to 11th, in the list of the most frequent causes of disability. (Vos 2013)



Australia

- More than half of the 1.8 million Australians with osteoarthritis were between 25 and 64 years old. *(Ackerman 2015)*
- An increasing incidence of sports injuries could result in an increasingly larger future burden of OA in the population, with a corresponding increase in health service delivery and musculoskeletal ill-health burden in future years. *(Finch 2015)*
- The costs of retiring early in Australia due to arthritis include over \$9 billion in lost gross domestic product, and additional societal costs are associated with reduced work productivity. *(Ackerman 2015)*
- While direct health care costs are often reported, indirect health care costs may be eight times greater than direct costs, indicating that the true burden of OA is underestimated. *(Finch 2015)*
- The cost of arthritic disease in Australia is estimated to be \$24 billion per annum, affecting one in eight adults. *(Finch 2015)*
- In Australia, 13 percent of primary total hip replacements and 7 percent of primary total knee replacements are undertaken in people under age 55. *(Ackerman 2015)*
- People undergoing total joint replacement are 26 percent more likely to have cardiovascular disease than people without OA. *(Finch 2015)*

United Kingdom

- Knee replacements are being performed much more frequently. There were more than 80,000 primary procedures in 2011, increasing by around 3 percent annually. *(Willis 2015)*
- Since 2006, the majority of knee replacement patients were obese (body mass index of 35 or greater) and this proportion is growing.
 - In 2006, 15 percent of patients were obese.
 - In 2013, 21 percent of patients were obese. *(Willis 2015)*
- There are around 5,000 (6 percent) revisions out of 88,000 total procedures in England each year. *(Willis 2015)*
- Younger, more active patients are at greater risk of implant failure, as are obese patients.
 - The need for revisions is bound to increase considerably with the increase in primary procedures and the tendency to operate on younger, more obese patients. *(Willis 2015)*

Spain

- In Spain, deprived areas have higher rates osteoarthritis (hand, hip and knee). OA patients in the most deprived areas were younger, had fewer women and a higher percentage of residents who were obese, smoked and considered high-risk alcohol consumers. *(Reyes 2015)*
- The increased prevalence of obesity accounts for 50 percent of the excess risk of knee OA observed. Public health interventions to reduce the prevalence of obesity in this population could reduce health inequalities. *(Reyes 2015)*

IN DEVELOPED NATIONS, OSTEOARTHRITIS (OA) IS ONE OF THE 10 MOST COMMON DISABILITIES IN OLDER INDIVIDUALS.

(Palmer 2015)



Arthritis Foundation

1 IN 3 MILITARY VETERANS IN THE U.S LIVES WITH ARTHRITIS

(CDC 2014)



Prevalence in the Military

- One of every three military veterans in the United States lives with arthritis. *(Murphy 2014)*
- A study of combat-injured soldiers found that osteoarthritis (OA) was the most common cause of disability and separation from military service. *(Rivera 2012)*
- About 94.4 percent of OA cases in military service members are attributable to combat injury. *(Rivera 2012)*
- The risk for U.S. active duty military personnel to develop OA increased from 2005 to 2014. The risk for knee OA increased for:
 - Increasing age
 - African-American race
 - Senior military rank
 - Service in the Army or Air Force *(Showery 2016)*
- The risk for military service members to develop hip OA is higher due to greater activity and occupational demand level compared to the general population for:
 - Those over 40
 - Lower-rank service members in the Army, Navy and Marines *(Scher 2009)*
- The rate of OA in military service members is:
 - 26 percent higher than the general population (age 20 to 24)
 - Twice as high as the general population (age 40 and older) *(Cameron 2011)*
- For service members 25 and older:
 - The overall rate of OA was higher among black, non-Hispanics than other racial/ethnic group members.
 - The rate of shoulder OA was higher among men than women. *(Williams 2016)*

- Among service members 30 and older:
 - Women had higher rates of OA of the knee and pelvic region/thigh than men. *(Williams 2016)*

Human and Economic Burdens

- Post-traumatic osteoarthritis (PTOA) is recognized as a disabling condition as soon as 20 months after injury. *(Rivera 2012)*
- The U.S. military has been engaged in active combat since 2001, the longest period of continuous active combat in U.S. history, resulting in over 14,000 service members evacuated from combat due to disease and injury.
 - Arthritis is the most frequent reason for medical discharge and among the most common conditions treated by Veteran Affairs health care facilities. *(Cross 2011)*
- For veterans with arthritis, and with arthritis plus back pain, there is a higher rate of diabetes, high cholesterol, high blood pressure and obesity, compared to veterans with no pain diagnosis.
 - Veterans with arthritis plus back pain had the highest pain clinic use and prescription use of opioids and anti-inflammatories. *(Rivera 2016)*
- PTOA is the most common indication for total knee reconstruction (TKA) among young military personnel 50 and younger.
 - For U.S. military personnel (2005-2013), 74 percent who had TKA had a previous injury before the development of end-stage PTOA. *(Murtha 2017)*

Global Burden for Military and Other Tactical Athletes

- Globally, the physical fitness and work-related demands of tactical athletes (people in service professions like the military, firefighters, law enforcement officers and first responders) have an increased risk of acute traumatic joint injury.
 - Their jobs require a lot of repetitive bending, squatting, kneeling and lifting, which can increase the chance of developing osteoarthritis. *(Cameron 2016)*



- In the U.S., military rank and branch of military service appear to be occupational risk factors associated with OA.
 - OA has consistently been a leading cause of military disability discharge for more than a decade, regardless of whether the estimates are from peacetime or periods of combat.
 - Compared to the general population, active duty military are significantly more likely to experience an OA diagnosis anywhere in the body, but especially in the knee and hip.
 - The prevalence of lumbar (back) and cervical (neck) OA were 49 to 76 percent higher in some military populations (like active duty pilots and veteran parachutists).
 - Those serving in the Army and the junior enlisted ranks experienced the highest rates of OA. *(Cameron 2016)*
- Swedish firefighters are about 2.5 to 3 times more likely to have knee or hip OA than the general population. *(Cameron 2016)*
- For Danish soldiers on combat duty in Afghanistan, the risk of suffering knee problems and the severity of symptoms increased with the amount of time spent patrolling in armored vehicles. *(Lundin 2016)*

POST-TRAUMATIC OSTEOARTHRITIS (PTOA) IS
RECOGNIZED AS A DISABLING CONDITION AS
SOON AS 20 MONTHS AFTER INJURY.

(Rivera 2012)



Section 3:

Autoimmune and Inflammatory Arthritis

A Related Group of Rheumatoid Diseases

A healthy immune system is protective. It generates internal inflammation to get rid of infection and prevent disease. But the immune system can go awry, mistakenly attacking the joints with uncontrolled inflammation, causing joint erosion and damage to internal organs, eyes and other parts of the body.

There are many types of arthritis that fall into the category of autoimmune inflammatory arthritis. This section presents the facts for some of the most common diseases in this group:

- Diseases commonly involving multi-system organ involvement including: rheumatoid arthritis (RA), systemic lupus erythematosus (SLE or lupus), Sjögren's syndrome, and scleroderma (systemic sclerosis)
- spondyloarthritis (SpA), an umbrella term for diseases primarily involving the joints, ligaments, and tendons that includes: ankylosing spondylitis and psoriatic arthritis (PsA).

The goal of treatment for these diseases is to reduce pain, improve function and prevent further joint damage.





IN 2015, ESTIMATED NATIONAL
INDIRECT COSTS OF RA-RELATED
ABSENTEEISM FROM WORK
WERE \$252 MILLION ANNUALLY.

(Gunnarsson 2015)



Eileen Schneider: Patient Partner's Words of Wisdom About Living With RAs

Meet Eileen Schneider, who is a registered nurse and has a passion for patient advocacy. Following, in her own words, is her story about living with rheumatoid arthritis (RA) and how the statistics she reviewed in *Arthritis by the Numbers* relate to her personally.

Question: How do some of the RA statistics you read about affect you?

Eileen: They're a reminder to me that this disease affects many people in many ways. Over the years, I've learned that a person doesn't "just have RA," because the disease affects other parts of the body, too. The numbers reinforce that RA is more than a physical disease and can also affect behavioral health. RA is difficult to cope with, and as the statistics reveal, depression is particularly common.

I seem to be an outlier when it comes to the impact RA can have on work. I have maintained full-time employment since I was diagnosed and have never had to call in sick because of my RA. I've had some surgeries on my joints, but even then, I was able to return to work promptly while recovering. There have been days when I haven't felt well, but I've learned that keeping myself busy has been a helpful coping strategy.

The cost burdens of living with RA are real. I have decent medical insurance, but prescriptions, copays and lab work are all costly. I had significant financial hardship from hand and wrist surgeries, and it took quite a while to pay off the out-of-pocket expenses. The benefits were terrific, but the financial strain increased stress.

Question: What changes has your arthritis made to the way you live?

Eileen: There have been significant changes. One of the biggest challenges was accepting that I could no longer be as independent as before. I grew up taking care of myself and figuring things out on my own. When I was diagnosed at age 27, I wasn't ready to give up that independence. Over time, I realized I no longer had a choice and had to ask for help if I needed it. That was a tough transition.

One of the biggest changes I had to make was in my line of work. I was in the prime of my nursing career when diagnosed. My rheumatologist told me that bedside nursing care would no longer be possible. I knew he was right, but it made me so sad. I could no longer open syringes, help turn a patient over, safely help someone walk who was weak. So, I became a nurse educator and have worked in the same hospital for 35 years in a variety of nurse-related roles. RA has made me a better nurse because I have greater understanding of those with chronic conditions.

Question: What advice would you give to a newly-diagnosed patient or parent/caregiver?

Eileen: Be patient with yourself. It takes a while to learn to live with it. Over time you will find the balance between living with RA but not letting it consume you. Some days I hardly think about it at all; other days I think about it a lot and feel down. I've learned to pay attention to what my body is telling me. I've learned that often when I'm feeling down, it's because of fatigue. My body is telling me to slow down, get more rest. Ask for help and listen to your body. Balance is key.



Rheumatoid Arthritis

Rheumatoid arthritis (RA) is an autoimmune disease in which the body's immune system mistakenly attacks the joints. This creates inflammation that causes the tissue that lines the inside of joints to thicken, resulting in swelling and pain in and around the joints.

If inflammation goes unchecked, it can damage cartilage, the elastic tissue that covers the ends of bones in a joint, as well as the bones themselves. Over time, there is loss of cartilage, and the joint spacing between bones can become smaller. Joints can become loose, unstable, painful and lose their mobility. Irreversible joint deformity can occur, so doctors recommend early diagnosis and aggressive treatment to control RA.

RA most commonly affects the joints of the hands, feet, wrists, elbows, knees and ankles, and is usually symmetrical. Because RA can also affect body systems, such as the cardiovascular or respiratory system, it is called a systemic disease, meaning "entire body."

Despite the many challenges of this disease, 87 percent of RA patients are optimistic and say they have access to a good health care team for their arthritis (source: 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation).

The following facts describe some of the features common to RA.

Prevalence

- In 2005, rheumatoid arthritis (RA) was estimated to affect 1.3 million adults in the U.S., representing 0.6 percent of the population. *(Helmick 2008)*

- By 2007, an estimated 1.5 million adults had RA. *(Myasoedova 2010)*

- The prevalence of RA is approximately 0.5 to 1 percent in developed countries and 0.6 percent in the U.S. population. *(Gabriel 2009)*

- Women are two to three times as likely to be affected as men. *(Vollenhoven 2009)*

- One in 12 women and one in 20 men will develop an inflammatory autoimmune rheumatic disease during their lifetime. *(Crowson 2011)*

Human and Economic Burdens

Health Burdens

- Mortality hazards are 60-70 percent higher in patients with rheumatoid arthritis (RA) compared with those in the general population.

- The overall survival gap between patients with RA and those without RA has not been closing over the past decades.

(Dadoun, 2013)

- However, the survival gap related to cardiovascular disease shows improvement in RA patients as compared to subjects without RA in recent years. *(Myasoedova, 2017)*

- A 2007 study found that excess mortality in RA has been seen in:
 - cardiovascular disease (31 percent)
 - pulmonary fibrosis (4 percent)
 - lymphoma (2.3 percent) *(Young 2007)*

- Psychiatric disorders in RA are common, particularly depression.
 - About 16.8 percent of RA patients suffer from depression, which is significantly greater compared with that of the general population. *(Matcham 2013)*

- For those with RA from 1987 to 2012:
 - Men with RA were hospitalized for depression at a greater rate than were men without RA.
 - Patients with RA were hospitalized at a greater rate for diabetes mellitus than were people without RA. *(Michet 2015)*

- Menopausal status is associated with worsening functional decline in women with RA.
 - Pre-menopausal women had less functional decline.
 - The use of hormonal replacement therapy, having a pregnancy and having a longer length of reproductive life were associated with less decline. *(Mollard 2018)*



- Adult patients with RA, regardless of age, are at high risk of falls as well as fall-related injuries and fractures.

- RA patients are at increased risk of osteoporotic fractures.

(Acurcio 2016)

- The risk of nonspinal fractures increases in RA patients who are treated with opioids.

- Risks of fracture associated with opioid use were more than six times higher between the first and third week of treatment.

- Clinicians caring for vulnerable adult patients with RA should carefully consider the risk of fractures associated with use of these medications, especially during the initial period of treatment. (Acurcio 2016)

Work/Employment Impact

- The lost productivity associated with rheumatoid arthritis (RA) is substantial.

- Because of its progressive nature, many individuals report missing work or choose not to work because of disease-related disabilities.

- Approximately 20 to 70 percent of individuals who were working at the inception of their RA were disabled after seven to 10 years. (Burton 2006)

- The indirect cost of RA due to lost productivity has been estimated to be nearly three times greater than the costs of treating the disease. (Agarwal 2011)

- A 2010 study found that about one-fourth to one-half of all patients with RA become unable to work within 10 to 20 years of follow-up after diagnosis. (Mikuls 2010)

A 2010 study found that about one-fourth to one-half of all patients with RA become unable to work within 10 to 20 years of follow-up after diagnosis.



(Agarwal 2016)

- Among those who did miss work, employees with RA missed more days than employees without the disease.

- In 2015, estimated national indirect costs of RA-related absenteeism from work were \$252 million annually.

(Gunnarsson 2015)

Medical/Cost Burdens

- Mortality rates attributable to rheumatoid arthritis (RA) have declined globally. Population aging combined with a fall in RA mortality may lead to an increase in the economic burden of disease that should be taken into consideration in policymaking. (Kiadaliri 2017)

- From 1987 to 2012 in Olmsted County, Minnesota:

- Patients with rheumatoid arthritis were hospitalized at a greater rate than were patients without RA.

- The increased rate of hospitalization was found in both sexes, all age groups, all calendar years studied and throughout disease duration. (Michet 2015)

- There were 323,649 hospitalizations for RA between 1993 and 2011.

- During this time, the annual hospitalization rate for patients with a principle discharge diagnosis of RA declined from 13.9 to 4.6 per 100,000 adults in the U.S. (Lim 2016)

- Based on 2005 U.S. Medicare/Medicaid data, total annual societal costs of RA (direct, indirect and intangible) increased to \$39.2 billion.

- The direct (\$8.4 billion) and indirect (\$10.9 billion) costs to RA patients translate to a total annual cost of \$19.3 billion.

- Intangible costs included quality-of-life deterioration (\$10.3 billion) and premature mortality (\$9.6 billion).

- From a stakeholder perspective, 33 percent of the total cost was allocated to employers, 28 percent to patients, 20 percent to the government and 19 percent to caregivers. (Birnbbaum 2010)

- A 2009 study found that:

- Almost half (43.6 percent) of RA patients had problems paying medical and drug bills after insurance payments.

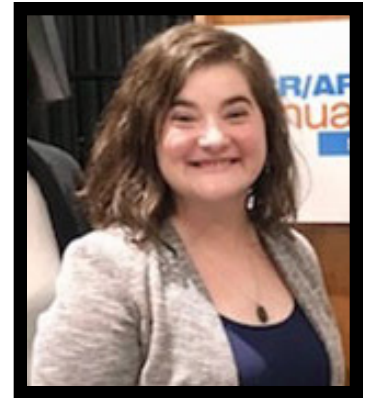
- About 9 percent reported a severe or great burden, being unable to purchase all the medications or care they needed because of out-of-pocket medical expenses.

- This burden was substantially greater for patients under age 65 (11.8 percent) compared with those 65 and older (5.3 percent). (Wolfe 2009)

Liz Morasso: Support Networks Helped Her Adjust to a New Life

Meet Liz Morasso, a licensed clinical social worker at UCLA's department of radiation oncology who has volunteered for the Arthritis Foundation since 2002. That's when, at age 16, she was diagnosed with systemic lupus erythematosus (SLE) and rheumatoid arthritis (RA). Over the years, she has immersed herself in leadership roles with the Foundation and speaks nationwide to inspire patients living with chronic illness.

Following, in her own words, is Liz's story about living with these conditions and how the statistics she reviewed in *Arthritis by the Numbers* relate to her personally.



Question: How do some of the arthritis statistics you read about affect you?

Liz: Being female and having SLE and RA rang true. More adult women are diagnosed with these diseases than men. My symptoms began in middle school, mostly depression and fatigue. I felt isolated, and my emotions and physical state were unpredictable. Even though I was active in afterschool activities, like the swim team, my fatigue was constant, and I started to develop joint and muscle pain.

About a month before my diagnosis, I jokingly told a friend, "It feels like I have arthritis." She thought I was kidding – after all, kids don't get arthritis. Not long after that, my Spanish teacher recognized my malar rash. The school nurse found that I had a fever, and my joints, muscles and lymph nodes were swollen and sore. I was referred to a pediatric rheumatologist.

Another fact that stood out to me was the number of patients who develop SLE before the age of 18. In my work with different arthritis groups, I am seeing more and more patients who are teenagers and young adults. The number of patients in this age group is rapidly growing. I hope better access to care and understanding of rheumatic disease will help them experience relief and support like I did.

Question: What changes has your arthritis made to the way you live?

Liz: It can be challenging to explain my disease in a way others can understand. This disease sometimes still feels like it is something for older people. I thought it was rare for young people to feel the way I felt. Initially, I was afraid to meet others who had RA or lupus.

Because my doctor was so involved with the Arthritis Foundation, she talked about ways it could help me. My friends and family also wanted to be supportive and help in fundraising and events. I started meeting others my age with the same experiences. They became my support network – my go-to for social engagement and information. I became a JA camp counselor. I'm glad I did, because it helped me meet people and find resources to help me cope and adjust to my "new" life.

Question: What advice would you give to a newly-diagnosed patient or parent/caregiver?

Liz: The turning point for me was connecting with fellow patients through the Arthritis Foundation. Connecting made me feel validated. Connecting helped me feel less isolated and more normal. Being part of the Arthritis Foundation community is important for a variety of reasons. It empowers you and those who love and care about you to find control.

Systemic Lupus Erythematosus (SLE or Lupus)

Lupus is a chronic, autoimmune disease. People with lupus have an overactive and misdirected immune system. Lupus is systemic, meaning it affects a wide part of the body, including the joints, kidneys, skin, blood, brain and other organs.

Systemic lupus erythematosus (SLE) accounts for about 70 percent of all lupus cases. While SLE generally is considered the most serious form of lupus, cases range from very mild to severe. SLE affects various parts of the body and can cause joint pain, fatigue, hair loss, sensitivity to light, fever, rash and kidney problems.

Despite the challenges of this disease, SLE patients remain optimistic. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 90 percent of these patients say they can meet the goals they set for themselves.

The following facts describe some of the features common to SLE.

Prevalence

- Women 15 to 44 years old are at greatest risk of developing systemic lupus erythematosus (SLE). (Dall'Era 2017)
 - Between 1970 and 2001, most new diagnoses of this disease – about 80 percent – were made in women between 15 and 44 years old. (Merola 2014)
- About 15 to 20 percent of all SLE cases develop before the age of 18. (Weiss 2012)
- Women are affected far more than men – about four to 12 women develop lupus for every man affected. (Dall'Era 2013)
- Both geography and race affect the prevalence of SLE, as well as the frequency of diagnosis and severity of the disease.
 - The disease appears to be more common in urban than rural areas in California and Pennsylvania. (Chakravarty 2007)

Racial Distribution

- Minority and ethnic groups are affected more than Caucasians. (Dall'Era 2017)
 - Minority women tend to develop lupus at a younger age, have more serious complications and higher mortality rates. (Gonzalez 2014)
- The prevalence (how widespread) and incidence (risk for the disease) of systemic lupus erythematosus (SLE) in the U.S. American Indian and Alaska native populations are as high as, or higher, than the rates reported for the African-American population. (Ferucci 2014)

- For U.S. American Indian and Alaska native populations:
 - Prevalence (how widespread SLE is):
 - o Overall, 178 per 100,000 people have SLE.
 - o Women are almost twice as likely to have SLE (271 per 100,000 people).
 - Incidence (the risk of developing SLE):
 - o The overall risk is 7.4 cases per 100,000 per year.
 - o Among women it's 10.4 cases per 100,000 per year. (Ferucci 2014)
- The prevalence of SLE is:
 - Higher in the U.S. among Asians, African-Americans, African-Caribbeans and Hispanic-Americans compared with Caucasians
 - Higher in the U.K. among Asian-Indians compared with Caucasians (Rus 2002)

In the U.S., studies suggest strong associations between ethnicity, socioeconomic status and outcomes of lupus.

- African-Americans, Hispanics and individuals of low socioeconomic status are at higher risk of negative health outcomes. (Crosslin 2009)

Geographic Distribution

- In Manhattan, New York:
 - Women have about nine times higher risk of having systemic lupus erythematosus (SLE) than men.
 - Non-Hispanic black women, Hispanic women and non-Hispanic Asian women are more likely to have SLE than Caucasian women. (Izmirly 2017)

- In San Francisco County, California:
 - Women have about eight times higher risk of having SLE than men.
 - The disease burden is highest in black women, followed by Hispanic women, Asian women and white women. *(Dall'Era 2017)*
- In Georgia, noticeable gender, age and racial disparities in SLE have been demonstrated.
 - Compared to men, women:
 - o are at five times higher risk of having SLE
 - o are diagnosed with SLE over eight times more often
 - The prevalence of SLE is three to four times higher in African-Americans than in Caucasians.
 - Disease onset occurs at a younger age among African-Americans. *(Lim 2014)*
- In Michigan, SLE prevalence is:
 - 2.3 times higher in African-Americans than in Caucasians
 - 10 times higher in females than in males *(Somers 2014)*
- International comparison of prevalence among all races shows:
 - In the U.S., 52.2 cases per 100,000 people
 - In the U.K., 26.2 cases per 100,000 people
 - In Japan, 28.4 cases per 100,000 people *(D'Cruz 2007)*
- International comparison of incidence among all races shows:
 - In the U.S., 5.1 per 100,000 people
 - In the U.K., 3.8 per 100,000 people
 - In Japan, 2.9 per 100,000 people *(D'Cruz 2007)*
- Patients report that treatments have limited effectiveness and are often associated with substantial negative effects. *(LPV 2018)*
- An increase in the damaging effects of lupus, disease complications and an increased risk of death may be associated with:
 - poor access to health care
 - late diagnosis
 - less effective treatment regimens
 - poor adherence to therapy *(Dall'Era 2013)*
- Lack of coordination and communication of patients' needs is associated with increased risk of severe infection and diagnosis of additional health conditions. These results suggest that improved health information exchange could positively impact health outcomes for systemic lupus erythematosus (SLE) patients. *(Walunas 2016)*
- Differences in disease presentation, severity and course can often be related to ethnicity, income level, education, health insurance status, level of social support and medication adherence, as well as environmental and occupational factors. *(Carter 2016)*
- Poverty, either current or at some time, plus severity of poverty, is associated with increased disease-related damage throughout the body in patients with SLE. *(Yelin 2017)*
- SLE patients are likely to endure considerably reduced health-related quality of life. *(Carter 2016)*

Human and Economic Burdens

- Many people with lupus experience challenges with identity and self-esteem, as well as a decrease in quality of life.
 - These issues may be made worse by the stigma of the disease. *(LPV 2018)*
- Friends, family and co-workers may not understand the impact of the disease, which has many invisible symptoms. *(LPV 2018)*

Comorbidities and Health Burdens

- Fatigue is the most common symptom affecting quality of life for people with this disease. *(Yazdany 2010)*
 - More than half of surveyed patients ranked fatigue and pain in joints and muscles as having the most impact on well-being. *(LPV 2018)*

- There is a direct relationship between fatigue in systemic lupus erythematosus (SLE) and the following:

- physical inactivity
- poor sleep quality
- negative mood, depression and anxiety
- cognitive dysfunction
- obesity
- vitamin D deficiency/insufficiency
- comorbidities such as fibromyalgia (Ahn 2012)

- Other symptoms patients noted as affecting their daily lives included:

- brain fog – forgetfulness and lack of concentration
- stomach and bowel symptoms
- sun sensitivity
- reduced physical strength
- increased susceptibility to infections
- depression or mood changes
- organ inflammation
- kidney disease or failure (LPV 2018)

- Global disease activity is not a risk factor for depression.

However, skin involvement and certain types of neurologic activity (myelitis, or inflammation of the spinal cord) are predictive of depression. (Huang 2014)

- Use of higher-dose prednisone (20 mg or more daily) is a risk factor for depression in lupus patients. (Huang 2014)

- Neuropsychiatric symptoms (mental or emotional complications) usually occur early in the development of SLE. (Hanley 2007)

- In SLE, neuropsychiatric involvement is associated with a lower quality of life and poor prognosis. (Hanley 2010)

- Some degree of cognitive dysfunction is present in up to 80 percent of patients with SLE. (Meszaros 2012)

- Brain abnormalities have been seen in 25 percent of newly-diagnosed SLE patients, suggesting that the brain may be affected extremely early, even before a diagnosis of SLE is made. (Petri 2008)

- Observational studies report the prevalence of obesity among adults with SLE at around 28 percent. (Chaiamnuay 2007)

- Serious infections are recognized as major causes of morbidity and mortality in patients with lupus, accounting for:

- 13 to 37 percent of hospitalizations
- 65 percent of avoidable hospitalizations
- One-third of deaths (Tektonidou 2015)

- SLE patients have two to five times the risk of death compared with the general population. (Fors Nieves 2016)

Kidney Involvement

- Glomerulonephritis (acute inflammation of the kidney) is seen in 30 to 50 percent of patients with systemic lupus erythematosus at diagnosis. Some degree of kidney involvement is observed in at least 60 percent with this disease. (Rajashekar 2008)

- Kidney damage is one of the main causes of morbidity and mortality in patients with SLE. (Rahman 2008)

lupus
accounts for
about **20%**
of the more
than estimated
1.5 million
Americans with a
work disability.



(Agarwal 2016)

- Lupus nephritis (kidney disease) is a severe manifestation of the disease, affecting up to 60 percent of patients at some point in their disease trajectory. *(Singh 2009)*
- The overall reported prevalence of end-stage kidney disease caused by lupus nephritis has increased 56 percent over the 10-year period of 2000 to 2010. *(NIH 2010)*
- The prevalence of kidney and cardiovascular damage in SLE is higher among African-Americans than in Caucasians.
 - African-Americans with SLE also experience these complications at earlier ages. *(Ward 2007)*

Joint Involvement

- Joint involvement is a central feature of systemic lupus erythematosus and is seen in 70 percent of children and 90 percent of adults with the disease. *(Tarr 2015)*
- About 44 percent of the hip and knee joints of SLE patients undergoing corticosteroid treatment display osteonecrosis lesions (a bone disease that results from loss of blood supply to the bone, causing the bone tissue to die and the bone to collapse). *(Nakamura 2010)*

Pregnancy Impact

- Pregnancies in women with lupus are associated with a higher risk of complications, higher health care costs and fewer prescribed medications, including immunosuppressants, than in healthy women. *(Petri 2015)*
- Maternal outcomes (such as pre-eclampsia, hypothyroidism, stroke and infection) are more common among women with systemic lupus erythematosus (SLE).
 - Sixteen percent of pregnant women with SLE were diagnosed with pre-eclampsia, compared with 5 percent of those from the general population.
 - Among the pre-SLE women, pre-eclampsia was found in 26 percent of those with SLE within two years postpartum and 13 percent in those with SLE within two to five years postpartum. *(Arkema 2016)*

- Infant outcomes, such as preterm birth, infection and mortality, were worse among those born to mothers with prevalent SLE and pre-SLE during pregnancy. *(Arkema 2016)*
- Adverse pregnancy outcomes (APO) occurred in 19 percent (almost one in five) of pregnancies in women diagnosed with lupus:
 - Fetal death occurred in 4 percent.
 - Neonatal death occurred in 1 percent.
 - Preterm delivery occurred in 9 percent.
 - Ten percent of neonates were small for their gestational age (birthweight was below the fifth percentile).
 - Maternal flares and higher disease activity also predicted the APOs. *(Buyon 2015)*

Employment/Economic Impact

- Systemic lupus erythematosus (SLE) is one of the leading causes of work disability in the U.S., accounting for about 20 percent of the more than 1.5 million Americans estimated to have a work disability. *(Agarwal 2016)*
- Patients often have reduced ability to perform work, care for their dependents and engage in other unpaid work.
 - Resulting indirect costs can exceed direct costs by two-to-four-fold. *(Choi 2016)*
- The longer a person has been diagnosed with SLE, the less likely they are to be part of the workforce.
 - Worldwide, about half of SLE patients of working age report being employed. *(Yazdany 2010)*
- One study showed that the number of hours a patient worked in a year decreased since the year of diagnosis, from 1,378.2 hours per year to 899.5 hours per year for people with SLE.
 - The mean income of working-age participants decreased from \$24,931 in the year of diagnosis to \$16,272 at the time of the study, representing a loss of \$8,659. *(Panopalis 2008)*



- Symptoms of lupus can have a profound impact on the person's employment, status in the workforce and in their personal life.
 - Impacts of lupus are more pronounced among young people and in middle adulthood.
 - Studies have shown that loss in work hours due to lupus symptoms costs the U.S. nearly \$13 billion annually.
 - Symptoms affect the individual's work, quality of life, self-management and self-efficacy. (Agarwal 2016)
- Studies from the U.S. reveal that 15 to 40 percent of SLE patients are unemployed within five years of diagnosis. (Drenkard 2014)
- According to a longitudinal survey of persons with SLE:
 - In the year of diagnosis, 76.8 percent of participants were employed.
 - Only 48.7 percent were employed at the end of the study. (Panopalis 2008)
- In a longitudinal study of about 900 predominantly middle-class white women with SLE, of those employed at diagnosis:
 - More than one-third had stopped working by 10 years after diagnosis.
 - Slightly more than half had stopped working by 15 years after diagnosis.
 - Just under three-quarters had stopped working by 25 years after diagnosis.
 - Almost no one in this study was employed to normal retirement age. (Yelin 2007)

- With many patients diagnosed in their mid-thirties, on average: If half of those employed stop work within 15 years of diagnosis, those individuals lose almost 20 years of their work lives. With this in mind, people with SLE are at greater risk of facing retirement in poverty. (Yelin 2007)

Medical/Cost Burdens

- Both direct medical costs associated with an individual's care and indirect costs such as loss of economic productivity are high. (Carter 2016)
- The medical costs of systemic lupus erythematosus (SLE) are substantial, with a mean total medical care cost of \$51,295 over four years. (Kan 2016)
- SLE flares were experienced by 97 percent of SLE patients, with an average of 2.6 flares per patient per year.
 - Cost per flare was highest for severe flares, at \$11,716.
 - Patients with at least one severe flare during the follow-up period had an annual cost of \$49,754.
 - Patients with at least one severe flare had more than twice the costs of patients with moderate or mild flares. (Kan 2013)
- In a study of U.S. Medicaid enrollees between 2000 and 2009, SLE patients had significantly higher health care utilization and higher overall expenditures than patients with no SLE.
 - SLE patients incurred \$10,984 more total cost per year.
 - Fifty-five percent of that was attributed to inpatient care. (Kan 2016)

BETWEEN 15 TO 40 PERCENT OF SLE PATIENTS ARE UNEMPLOYED WITHIN FIVE YEAR OF DIAGNOSIS.

(Drenkard 2014)



- From 2000 to 2009, most SLE direct costs were related to:
 - inpatient care (16 to 20 percent)
 - outpatient services (24 to 56 percent)
 - medications (19 to 30 percent) *(Slawsky 2011)*
- Hospitalization rates for serious infections in SLE increased substantially between 1996 and 2011.
 - In 2011, SLE patients were over 12 times more likely to be hospitalized than patients without SLE.
(Tektonidou 2015)
- Between 2000 and 2010 in the U.S.:
 - The mean annual direct costs of SLE patients ranged from \$13,735 to \$20,926.
 - o With nephritis, costs ranged from \$29,034 to \$62,651.
 - o Without nephritis, costs ranged from \$12,273 to \$16,575. *(Slawsky 2011)*
- Across studies of a general SLE population:
 - Pharmaceutical costs comprised 19 to 30 percent of total expenditures.
 - Inpatient costs accounted for 16 to 50 percent of overall costs.
 - Outpatient costs accounted for 24 to 56 percent of overall costs. *(Slawsky 2011)*

HOSPITALIZATION RATES FOR SERIOUS INFECTIONS IN SLE INCREASED SUBSTANTIALLY BETWEEN 1996 AND 2011.

(Tektonidou 2015)

Sjögren's Syndrome

Sjögren's syndrome is a chronic, autoimmune disease that causes dryness of the eyes, mouth and other body parts.

In an autoimmune disease, the immune system mistakenly attacks healthy tissue, leading to inflammation in the body. In Sjögren's syndrome, the infection-fighting cells of the immune system attack the normal cells of glands that produce moisture and other parts of the body. This damages glands, making them unable to produce moisture. In addition to affecting the eyes and mouth, the disease can affect the skin (abnormally dry skin), joints (inflammatory arthritis), lungs, kidneys, blood vessels (purpura, Raynaud's disease), digestive organs (disorders of the esophagus, stomach, intestines, liver, and pancreas), the throat and larynx (voice-related disorders), and the nervous system.

The disease is classified either as:

- **Primary Sjögren's.** The condition exists as an individual rheumatic disease, but may also be seen with other autoimmune non-rheumatic and/or non-glandular diseases, such as autoimmune thyroid disease or celiac disease.
- **Secondary Sjögren's.** It overlaps with another rheumatic disease, such as rheumatoid arthritis.

Prevalence (Primary Sjögren's Syndrome)

- It's estimated that 4 million people in the U.S. are affected by Sjögren's syndrome.
 - It often remains undiagnosed or is misdiagnosed because the cardinal symptoms of dry eyes and dry mouth are common in the population and have multiple potential causes.
 - Primary Sjögren's syndrome is an autoimmune chronic inflammatory disorder affecting 0.2 to 3 percent of the population.
 - Nine out of 10 patients are women. *(Reksten 2014)*
- Although the average age of onset of primary Sjögren's syndrome is usually in the patient's 40s to 50s, onset of the disease can occur in the 60s or 70s. *(Patel 2014)*
- While Sjögren's syndrome can affect patients of any age, the prevalence of primary Sjögren's syndrome in the elderly population is between five to eight times higher than in younger and middle-aged adults. *(Patel 2014)*
- Sjögren's syndrome (SS) is rare but becoming more evident in juvenile patients.
 - Only 145 cases of primary juvenile SS have been reported in recent international pediatric literature.
 - About 5 percent of adult SS patients indicated they had symptoms before the age of 12.
 - Juvenile SS affects seven times more girls than boys.
 - The average age of juvenile SS onset is 10. *(Movva 2014)*

Comorbidities (Secondary Sjögren's Syndrome)

- Sjögren's is the most frequent disorder that occurs in conjunction with other autoimmune and rheumatic diseases. *(Hammitt 2014)*
- About half of the time, Sjögren's syndrome (SS) occurs alone, and the other half it occurs in the presence of another connective tissue disease, such as rheumatoid arthritis, lupus or scleroderma. *(SSF 2017)*
- The most frequent autoimmune diseases observed in SS patients are thyroid disease, rheumatoid arthritis and systemic lupus erythematosus. *(Anaya 2016)*

About **4 million**
people in the U.S. are affected by
Sjogren's Syndrome.

(Reksten 2014)

- If a Sjögren's patient has another major rheumatic, autoimmune disease, such as lupus, rheumatoid arthritis, scleroderma or multiple sclerosis, they are often categorized as having "Secondary Sjögren's."
 - However, this terminology is confusing and often inaccurate, implying that one disease is secondary to another. For example, patients with Sjögren's syndrome may have clinical and laboratory features that overlap with those of another systemic rheumatic disease when they first present, or may develop signs and symptoms of a second systemic rheumatic disease years after the initial development of SS.

(Hammit 2014)

Human and Economic Burdens

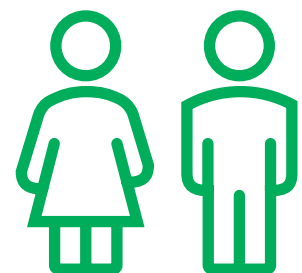
Health Burdens

- The disease's predominant effects are on the tear and salivary glands, as well as other moisture producing glands in the larynx (hoarseness), trachea (cough), skin (pruritus) and possibly the genital area (dyspareunia). (Baldini 2014)
- A 2016 survey of nearly 3,000 adult Sjögren's syndrome (SS) patients indicated that common symptoms experienced almost weekly or more frequently include:
 - dry mouth (92%)
 - dry eyes (92%)
 - fatigue (80%)
 - dry or itchy skin (76%)
 - morning stiffness (69%)
 - trouble sleeping (67%)
 - joint pain (64%)
 - dry nose/sinuses (63%)
 - forgetfulness (60%)
 - brain fog (57%) (SSF 2017-B)
- Up to 75 percent of patients with primary SS suffer from diseases that affect:
 - the skin (abnormally dry skin)
 - joints (inflammatory arthritis)
 - lungs
 - kidneys
 - blood vessels (purpura, Raynaud's disease)
 - digestive system
 - nerves (peripheral neuropathy) (Baldini 2014)

- Up to 25 percent of patients with primary SS develop moderate or severe disease that affects parts of the body other than the tear and salivary glands. (Baldini 2014)
- The prevalence of fatigue among patients with SS may be as high as 65 to 70 percent. (Haldorsen 2011)
- According to patients, those with severe dryness also have severe fatigue. (SSF 2017-B)
- Fatigue related to SS has been reported to be continuously present and patients say they never feel refreshed.
 - Some patients reported disturbed sleep caused by increasing stiffness and aching. Others slept so deeply that they did not notice the stiffness until they woke up, but even then, they were still tired.
 - Patients with fatigue related to primary SS feel a lack of vitality, but fatigue also varied during the day and from day to day in an unpredictable and uncontrollable way. (Mengshoel 2014)
- Sjögren's patients report that fatigue is different from tiredness.
 - Fatigue caused by Sjögren's doesn't always lead to sleep at night.
 - Fatigue from poor sleep/sleep disturbances causes patients to feel low in mood, and they experience more worry and pain. (Hackett 2018)

Primary Sjögren's syndrome is an autoimmune inflammatory disorder with a 9:1 female to male ratio.

(Reksten 2014)





PATIENTS WITH FATIGUE RELATED TO
PRIMARY SJÖGREN'S SYNDROME FEEL A
LACK OF VITALITY, BUT FATIGUE ALSO
VARIED DURING THE DAY AND FROM
DAY TO DAY IN AN UNPREDICTABLE
AND UNCONTROLLABLE WAY.

(Mengshoel 2014)



- Many Sjögren's patients experience "brain fog" – a fluctuating mild memory loss that is not appropriate for a patient's age. However, brain fog can be caused by different factors and should be evaluated by a health care provider. *(SSF 2018)*
- Brain fog is often experienced as problems with:
 - memory or difficulty focusing
 - processing information or numbers
 - paying attention
 - feeling not quite "all there" mentally *(McDermott 2003)*
- Brain fog generally is a different type of "dementia" than Alzheimer's disease and is not likely to land a person in a nursing home for chronic care. *(McDermott 2003)*
- Neurological issues seem to affect about 20 percent of patients with primary Sjögren's syndrome (pSS).
 - It is not uncommon for them to occur before other signs and diagnosis of pSS. *(Carvajal 2015)*
- Sjögren's can cause nerve damage (autonomic neuropathy) involved in regulation of heartbeat, breathing and movement of food through the digestive track. Symptoms include:
 - lightheadedness when standing
 - increased or decreased sweating
 - feeling full after eating a small meal *(Birnbaum n.d.)*
- The most common central nervous system syndromes seen in Sjögren's patients include inflammation of the spinal cord (myelitis) and inflammation of the nerves connecting the eye to the brain (optic neuritis).
 - Myelitis and optic neuritis can also occur in multiple sclerosis (MS) patients, sometimes confusing the diagnosis of the two diseases.
 - MS treatments may cause flares of Sjögren's syndrome. *(Birnbaum n.d.)*
- Autoimmune thyroid diseases have been observed in 45 percent of SS patients. *(Perez 1995)*
- High blood pressure and high cholesterol are more common in primary SS patients.
 - They also have an increased risk of cerebrovascular events (such as strokes and aneurysms) and heart attacks. *(Bartoloni 2015)*
- Patients with primary Sjögren's syndrome have an increased risk of developing non-Hodgkin B cell lymphoma, with a recent study showing a cumulative risk at 15 years after diagnosis of 9.8 percent. *(Solans-Laqué 2011)*
- The increased risk of developing non-Hodgkin B cell lymphoma is higher than that of patients with rheumatoid arthritis and systemic lupus who also have an increased risk of developing non-Hodgkin lymphoma. *(Nocturne 2015)*
- Individuals with SS frequently experience voice disorders and specific voice-related symptoms (e.g., frequent throat-clearing, throat soreness, difficulty projecting and vocal discomfort) that are associated with reduced quality of life. *(Tanner 2015)*
- Sjögren's syndrome is an autoimmune disease that affects exocrine glands and therefore may affect the gastrointestinal system, from the mouth, esophagus and bowel to the liver and pancreas.
 - Indigestion (including upset stomach, heartburn, acid reflux and nausea) is found in up to 23 percent of SS patients.
 - Patients may have rare pancreatic involvement that includes pancreatitis and pancreatic insufficiency.
 - Abnormal liver tests are found in up to 49 percent of SS patients, but they are usually mild. *(Ebert 2012)*
- Sjögren's patients are prone to developing a newly recognized type of reflux where acidic gastric contents move into the upper part of the esophagus and windpipe, causing local symptoms and changes in the voice and/or vocal cord tissues. *(Mavragani 2010)*
- Dry eye from SS can cause ocular complications, including corneal ulceration and scarring, as well as bacterial corneal and eyelid infections, requiring continuous medical care and treatment. *(Mavragani 2010)*



- Dry mouth from SS can increase the incidence of oral infections, cavities and other dental problems due to the loss of the lubricating, buffering and antimicrobial capacities of saliva.

(Mavragani 2010)

Secondary Sjögren's Syndrome With Rheumatoid Arthritis

- Secondary Sjögren's syndrome (SS) patients have a more severe form of arthritis.
- Secondary SS patients have significantly longer disease duration and higher disease activity, which might be associated with the higher incidence of anemia.
- The incidence of anemia is higher in secondary SS patients than in rheumatoid arthritis or in primary SS patients.
- The incidence of coronary heart disease and cardiovascular events is higher for secondary SS patients than for patients with rheumatoid arthritis alone.
- Interstitial lung disease, a common lung complication associated with rheumatoid arthritis (RA), is also more likely to be found in RA patients with secondary SS.
- About 4 to 31 percent of patients with RA meet the diagnostic criteria for secondary Sjögren's syndrome. However, about 30 to 50 percent of RA patients may have dry eye or mouth, but do not meet the full criteria for secondary SS diagnosis. (He 2013)

Secondary Sjögren's Syndrome With Lupus:

- Sjögren's syndrome (SS) patients with lupus are more often older, white women with photosensitivity, oral ulcers, Raynaud's phenomenon and antibodies commonly found in patients with autoimmune diseases (anti-Ro antibodies, and anti-La antibodies).
- SS patients with lupus have a lower frequency of renal disease and antibodies commonly found in lupus patients (anti-dsDNA antibodies and anti-RNP antibodies) than lupus patients without SS. (Baer 2010)

Sjögren's syndrome With Fibromyalgia

- In Sweden, there was an 82 percent increase in patients with Sjögren's syndrome and fibromyalgia (FM) having work disability two years after diagnosis, compared to 30 percent of patients with FM alone. (Mandl 2017)

Juvenile-onset Sjögren's Syndrome

- Sjögren's syndrome (SS) symptoms may be different in juvenile patients than in adults.
 - Juvenile SS patients show recurring gland (parotid) swelling and fewer dry eye/dry mouth symptoms. (Mowva 2014)
- Disease-related antibodies may be found in the blood that indicate SS in some juvenile patients who don't have dry eye or dry mouth symptoms.
 - These patients are diagnosed with subclinical SS. (Smolik 2017)

BRAIN FOG
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"DEMENTIA" THAN
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LAND A PERSON
IN A NURSING
HOME FOR
CHRONIC CARE.

(McDermott 2003)



Work/Employment Impact

- Sleep disruption from Sjogren's can interfere with occupational performance and impact daytime fatigue.
 - Patients report an impact on, and a relationship between, sleep and other Sjogren's symptoms.
- Sleep disturbances make other symptoms feel worse, affecting sleep and creating a vicious cycle.
 - o Comorbidities (additional chronic health issues) contribute to sleep difficulties, making all symptoms worse and resulting in further sleep problems.
- Poor sleep limits the ability to participate and perform daily activities; improvements in sleep may positively influence symptoms and improve participation. (Hackett 2018)
- Work disability, including sick leave and disability pension, is significantly higher among patients with primary Sjögren's syndrome (SS) than in the general population. (Dumusc 2017)
- Work disability is only a part of the indirect costs that could be underestimated in primary SS because most patients:
 - are female
 - are more likely to be engaged in unpaid and under-recognized activities that are of value to society (like housework, caring for children or parents, or voluntary activities) (Dumusc 2017)
- A study in Sweden showed:
 - At the time of diagnosis, 16 percent of patients with primary SS were already receiving a disability pension, and 10 percent were on sick leave.
 - After diagnosis, there was a steady increase in work disability, initially including sick leave, then including disability pension.
 - At two years after diagnosis, 41 percent were receiving a disability pension. (Mandl 2017)

Medical/Cost Burdens

- Patients report that living with Sjögren's adds a significant financial impact to their life.
 - Patients said they spent the most on dental care, followed by prescription medications and health care appointments/copayments. (SSF 2017-B)

Direct costs of primary Sjögren's syndrome (SS) based on claims database information from 10,000 patients in the U.S. found that annual health care costs in the year following diagnosis increased by 40 percent to \$20,416 per person. (Birt 2016)

Secondary SS patients require more therapy during treatment and incur higher hospitalization costs due to the higher incidence of anemia. (He 2013)

NEUROLOGICAL
ISSUES SEEM TO
AFFECT ABOUT 20
PERCENT OF
PATIENTS WITH
PRIMARY
SJÖGREN'S
SYNDROME (PSS).

(Carvajal 2015)

Scleroderma

Scleroderma, which means “hard skin,” affects about 300,000 Americans. Scleroderma involves the buildup of scar-like tissue in the skin, but it can also damage the cells in the walls of the small arteries. It is not contagious, infectious or cancerous. Scleroderma may occur in two forms - localized scleroderma and systemic sclerosis.

Systemic sclerosis tends to be the more severe form of this disease, but fewer people are affected by it. Systemic sclerosis may be classified as either limited or diffuse.

- **Limited scleroderma.** This kind affects the skin on the face, fingers and hands, and lower arms and legs. For many, the first symptoms are Raynaud’s phenomenon and puffy fingers, which can begin several years before other symptoms. If internal organs are involved, it tends to be mild. However, some people experience severe Raynaud’s phenomenon, gastrointestinal problems or serious effects on the lungs.
- **Diffuse scleroderma.** Skin thickening is widespread. It may affect any part of the body, especially the hands, arms, thighs, chest, abdomen and face. Itching, decreased flexibility and pain can also occur. Diffuse scleroderma may affect the blood vessels, heart, joints, muscles, esophagus, intestines and lungs. Kidney problems may lead to high blood pressure and, if untreated, kidney failure. Lung damage is the leading cause of death with this condition.

Prevalence

- The prevalence of scleroderma in the U.S. seems to be stable, with 240 cases per million adults. (Mayes 2003)
- Most adults with systemic scleroderma are diagnosed between the ages of 30 and 50. (Mayes 2003)
- Localized scleroderma (LS) has several subtypes. Plaque morphea, the most common adult subtype, occurs in about 60 percent of adults with LS. (Zulian 2006)
- Scleroderma does not occur randomly in the population; there are groups who are at greater risks.
 - Women are affected 4.6 times more often than men.
 - Scleroderma occurs more frequently in African-Americans than in whites. In addition, scleroderma is diagnosed at a younger age in African-Americans. (Mayes 2003)
- The highest reported prevalence of scleroderma in the U.S has been reported in a Choctaw Indian group in Oklahoma. (Arnett 1996)

Human and Economic Burdens

Health Burdens

- Mild renal (kidney) problems are not uncommon in systemic sclerosis. Scleroderma-related renal crisis occurs in about 15 percent of adult patients. (Torok 2012)

- The presence of pulmonary arterial hypertension (PAH) in scleroderma patients has a detrimental impact on survival. (Fischer 2012)

- The presence of pulmonary arterial hypertension (PAH) in connective tissue disease patients accounts for up to 30 percent of all cases of PAH, with most cases found in scleroderma patients. (Coghlan 2006)

The average annual medical costs of **SCLERODERMA** is more than **3 times** higher than costs for patients without the disease.

(Furst 2012)





- Pulmonary arterial hypertension is estimated to occur in 10 to 15 percent of adults with scleroderma. *(Martini 2006)*
- Patients with diffuse scleroderma are about five to eight times more likely to die, compared to people of the same age or gender of the general population. *(Mayes 2003)*
- Survival is strongly dependent on the degree of internal organ involvement. The average 10-year survival rate for adults is now 70 to 80 percent. *(Korn 2003)*
- Progressive pulmonary fibrosis, pulmonary hypertension, severe gastrointestinal involvement and scleroderma heart disease are the main causes of death. *(Mayes, et al 2003)*

A 1997 STUDY OF COSTS FOR SCLERODERMA SHOWED THE ANNUAL DIRECT AND INDIRECT COSTS OF SCLERODERMA IN THE U.S. WERE \$1.5 BILLION (ABOUT \$2.3 BILLION IN 2017 DOLLARS).

(Wilson 1997)

Economic Burdens

A 2012 study showed that the average annual medical costs in the U.S. for systemic sclerosis patients were more than three times higher than costs for patients without systemic sclerosis.

- Patients with serious disease complications from lung disease, gastrointestinal bleeding or renal disease experience the highest costs. *(Furst 2012)*

A 1997 study of costs for scleroderma showed the annual direct and indirect costs of scleroderma in the U.S. were \$1.5 billion (about \$2.3 billion in 2017 dollars). *(Wilson 1997)*

- A 2010 European study showed that the average yearly direct medical, nonmedical and indirect (work productivity loss-related) costs were higher for systemic sclerosis patients than for rheumatoid arthritis and/or psoriatic arthritis patients.

(Miner 2010)

- A 2008 Canadian study of costs for systemic sclerosis showed:

- The average direct cost per patient was \$5,038 per year.
- The average indirect costs – the value of potential productivity loss related to paid labor – was estimated at \$5,345 per patient per year.
- The cost of lost productivity related to unpaid labor contributed another \$8,070 per patient annually.
- The average total annual cost was estimated at \$18,453 per patient.
- Total annual costs were strongly associated with younger age, greater disease severity and poorer health status.

(Bernatsky 2009)

Spondyloarthritis (SpA)

Spondyloarthritis is an umbrella term for inflammatory diseases that involve the joints, ligaments, and tendons. The most common of these diseases is ankylosing spondylitis. Others include reactive arthritis, psoriatic arthritis and enteropathic arthritis, which is associated with the inflammatory bowel disease.

Spondyloarthritis has two main symptom patterns. Spondyloarthritis, in most cases, primarily affects the spine. For most people, the first and predominant symptom is low back pain.

Some forms can affect the peripheral joints -- those in the hands, feet, arms and legs. Peripheral spondyloarthritis is the less common symptom pattern. The main symptom is swelling in the arms and legs.

Joint inflammation often comes and goes and is accompanied by fatigue. Other problems can occur along with spondyloarthritis, including osteoporosis, pain and redness of the eye, inflammation of the aortic heart valve, intestinal inflammation and the skin disease psoriasis.

Prevalence

- Spondyloarthritis (SpA) is a group of interrelated diseases with different rates of prevalence. The overall prevalence of SpA in the U.S. ranges between 0.9 to 1.4 percent. *(Stolwijk 2012)*

- Prevalence for two of the most common forms of SpA is estimated at:

- Up to 1.7 percent for ankylosing spondylitis
- Up to 0.4 percent for psoriatic arthritis *(Stolwijk 2012)*

- Axial spondyloarthritis (AxSpA) prevalence – those forms that affect primarily the back and/or pelvis) – may be similar to that reported for rheumatoid arthritis.

- The overall number of people with AxSpA in the U.S. ranges between an estimated 1.7 million and 2.7 million persons.

(Reveille 2012)

Ankylosing Spondylitis Prevalence

- Ankylosing spondylitis (AS) occurs twice as often in men than in women.

- About 80 percent of patients have AS symptoms at or before age 30.
- About 5 percent of patients will present with AS symptoms at 45 or older. *(Louie 2017)*

- Ankylosing spondylitis (AS) is more common in Caucasians than other races.

- The prevalence is typically associated with the presence of the human leukocyte antigen (HLA) B27 gene.

- About 90 percent of North American Caucasians with AS carry the HLA B27 gene. *(Bunyard 2010)*

- The chances of developing ankylosing spondylitis is five to 16 times greater if a parent, child or sibling has the disease.

(Bunyard 2010)

- Although rare, juvenile ankylosing spondylitis can begin in childhood.

- Children and adolescents with this disease tend to have more peripheral arthritis than adults.

- Their arthritis typically involves lower extremity joints (knees, feet, etc.) and do not necessarily involve joints on both sides of the body. *(SAA 2018)*

Human and Economic Burdens

Human Burdens

- Patients with ankylosing spondylitis are at a 30 to 50 percent increased risk of incident cardiovascular events. *(Eriksson 2016)*

- Ankylosing spondylitis (AS) is a chronic inflammatory form of spondyloarthritis that often results in lower back pain early in the disease and can eventually lead to new bone formation that fuses the bones in the spine. *(Louie 2017)*

- Fusing of the back's bones in AS patients results in impaired spinal mobility.
 - For many AS patients, the fusing begins at the sacroiliac joints and progresses up from the lumbar spine to the neck.
 - Fusion can occur at any part of the spine, and sometimes the bone fusion may skip some joints but continue to move up.

(Louie 2017)

- Ankylosing spondylitis is responsible for 4 to 5 percent of patients with chronic low back pain. (Bunyard 2010)

- AS can be systemic, affecting more than just the back and sacroiliac joints. Some patients have:
 - dactylitis (sausage digit), Achilles tendinitis and plantar fasciitis
 - eye involvement (uveitis or conjunctivitis), affecting 20-40 percent of AS patients
 - cardiovascular disease
 - lung disease (including decreased chest expansion)
 - colitis and inflammatory bowel disease
 - spinal cord compression and cauda equina syndrome
 - osteoporosis (compression fractures possible with minimal trauma)
 - fatigue and malaise (Bunyard 2010)

- Juvenile ankylosing spondylitis (AS) can be mistakenly diagnosed as other forms of juvenile arthritis due to common symptoms like uveitis, diarrhea, pulmonary disease and heart disease.
 - Ineffective treatment of this childhood disease results in disease progression to the typical adult form of AS. (Adrovic 2016)

- There is no known cure for ankylosing spondylitis. The goals of treatment are to reduce pain and stiffness, slow progression of the disease, prevent deformity, maintain posture and preserve function. (Bunyard 2010)

- Back pain may improve with exercise, but pain increases with rest.
 - All patients with AS should have physical therapy to improve mobility and physical functioning.
 - Nonsteroidal anti-inflammatory drugs (NSAIDs) are nearly always used in conjunction with physical therapy. (Louie 2017)

- Physical therapy and supervised exercise programs have been found to be better than at-home versions for treatment of AS.

- Patient education programs can increase understanding of and compliance with physical therapy and exercise.
- Patients should be encouraged to quit smoking, which is associated with poorer health outcomes. (Dagfinrud 2005)

- While surgical intervention is rare, total hip replacement is the most common surgery for patients with AS. (Sweeney 2001)

- There are four anti-TNF, FDA-approved drugs for treating AS: adalimumab, etanercept, golimumab and infliximab. AS patients who used anti-TNF drugs for up to 24 weeks had:

- improvement in pain, function and inflammation, as measured by morning stiffness and patient overall well-being (about 40 percent)
- partial remission (10 to 44 percent)
- slight improvement in spinal inflammation, as measured by MRI (Maxwell 2015)

Economic Burdens

- Work disability affects 10 to 20 percent of patients with ankylosing spondylitis, most often in those with physically-demanding jobs. Lost income and lost productivity due to work disability represent major economic difficulties to both families and society. (Reveille 2012)

**Ankylosing
spondylitis**
is responsible for
4 to 5%
of patients with
chronic low back pain.

(Furst 2012)



Karen Lomas: Nurse With Psoriatic Arthritis: “Take Care of Yourself”

Meet Karen Lomas, 65, who works full time as a nurse. Following, in her own words, is Karen’s story about living with psoriatic arthritis (PsA), which she was diagnosed with several years ago, and how the statistics she reviewed in *Arthritis by the Numbers* relate to her personally.

Question: What do the statistics you reviewed mean to you and adjustments you’ve had to make?

Karen: I have been a member of the Arthritis Foundation since reading *Arthritis Today* magazine in my rheumatologist’s office years ago. I’ve taken part in local Jingle Bell Run and Walk to Cure Arthritis events. I was very surprised at the number of patients who have been diagnosed with, not just PsA, but all forms of arthritis. I expected the number of people with osteoarthritis to be high, but I had no idea the numbers were so high for other forms of arthritis.

Question: What changes has your arthritis made to the way you live your life?

Karen: That depends on a day-by-day basis, on how well the medications are working. On some days I have a hard time watching my grandchildren because my hands hurt. Nursing can be physically demanding. While I work full-time in the surgical department, I don’t work in surgery because I have a hard time hanging IV bags and it’s not easy to get on my hands and knees when needed.

I am getting closer to retirement age and am concerned about Medicare coverage. Because I currently have health care coverage through my employer, I can give myself shots at home once a week. Medicare won’t pay for that, and many places won’t take secondary supplemental insurance cards for this treatment option. So, you must pay out-of-pocket and wait to get reimbursed.

This medicine is not cheap. Medicare will pay for infusions of the drug, but that requires you to come into a clinic up to eight hours weekly, which would be a real burden. So, I plan to work longer, even though my arthritis makes me feel more fatigued. It’s less of a burden than trying to pay for medication on a fixed income..

Question: What advice would you give to a newly-diagnosed patient or parent/caregiver?

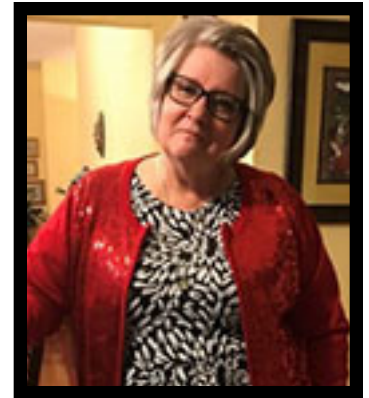
Liz: Take care of yourself and be informed. The more you can educate yourself and understand your disease, the better. Working on diet is a good thing – find out about anti-inflammatory diets. *Arthritis Today* and the Arthritis Foundation website have a lot of helpful information.

There is a shortage of rheumatologists, especially in rural areas. Be careful, because some well-meaning but ill-informed primary care doctors may prescribe ineffective or bad treatments like steroid shots. Long-term steroid use can be harmful.

Question: What are the questions we can’t answer yet, but you would like researchers to focus on?

Liz: I would like to see researchers develop a pill instead of using shots or infusions, especially for squeamish patients. I would also like to see researchers focus on incorporating more natural homeopathic treatments.

I thank the Arthritis Foundation for the opportunity to be involved. The Foundation allows me to give what I can and to help other patients. I want us to be more visible to others. Maybe focus on more celebrity spokespeople who have different forms of arthritis.



Psoriatic Arthritis (PsA)

Some people might hear “psoriasis” and think of the skin disease that causes itchy, scaly rashes and crumbling nails. It is true, psoriasis is a skin disease. But about 30 percent of people with psoriasis also develop a form of autoimmune, inflammatory arthritis called psoriatic arthritis (PsA), which can lead to joint pain, stiffness and swelling. It can affect the entire body and may result in permanent joint and tissue damage if not treated early and aggressively.

The disease may lay dormant in the body until triggered by some outside influence, such as a common throat infection. Yet for the most part, these patients remain optimistic. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 96 percent of PsA patients say that even when others get discouraged, they know they can find a way to solve the problem.

The following facts describe some of the features common to PsA.

Prevalence

- The presence of psoriasis, inflammatory arthritis and absence of positive serological tests for rheumatoid arthritis are the hallmarks of psoriatic arthritis (PsA).
 - Most people with PsA (60 to 70 percent) are diagnosed with psoriasis first.
 - In 15 to 20 percent of PsA patients, arthritis precedes the onset of psoriasis. *(Kerschbaumer 2016)*
- Up to 30 percent of individuals with psoriasis may also develop psoriatic arthritis, an inflammatory form of arthritis that can lead to irreversible joint damage if left untreated. *(Gladman 2005)*
- In the U.S., psoriasis remains a common, immune-mediated disease, affecting 7.4 million adults. Its prevalence has remained stable since the mid-2000s. *(Rachakonda 2014)*
- Psoriasis frequency ranges from 1 to 3 percent in Caucasian populations.
 - Psoriatic arthritis occurs in 10 to 40 percent of psoriasis patients. *(Ogdie 2015)*
- Psoriatic arthritis has a prevalence of:
 - 0.05 to 0.25 percent of the general population
 - Six to 41 percent of patients with psoriasis *(Ogdie 2015)*
- Psoriatic arthritis has a higher prevalence in patients with more extensive skin disease and a prevalence as high as 30 percent in dermatology clinics (where patients tend to have more extensive/severe psoriasis). *(Ogdie 2015)*
- Psoriatic arthritis is underdiagnosed in psoriasis patients, which may be due to underrecognition of PsA symptoms and a lack of effective screening tools. *(Liu 2014)*
- In seven European and North American countries, almost a third of patients with psoriasis seen in dermatology centers had psoriatic arthritis, as determined by rheumatologists.
 - Of the patients given the diagnosis of PsA in this study, 41 percent had not received a previous PsA diagnosis, suggesting underdiagnosis of patients in dermatologic practices of this potentially debilitating disorder. *(Mease 2013)*

Human and Economic Burdens

Health Burdens

- Patients with psoriatic arthritis experience pain, swelling and joint tenderness, which cause reduced functioning in daily activities and impaired quality of life. *(Strand 2012)*
- Patients with PsA report a substantial impact of disease on physical function.
 - One-third of surveyed PsA patients report missing work because of their disease and an impact on their ability to work full time.
 - Over half report receiving no treatment or topical therapy only, leaving joints untreated.
 - Patients report they are less likely to follow treatment guidelines due to perceived lack of efficacy and concerns about long-term safety. *(Kavanaugh 2016)*

- Skin symptoms of psoriasis can precede the joint symptoms of psoriatic arthritis by between 8 to 10 years. *(Kavanaugh 2016)*
- Nail involvement occurs more often and is more severe in patients with PsA than with psoriasis alone.
 - Nail involvement in psoriasis patients may predict the development of PsA. *(Kavanaugh 2016)*
- Severe psoriasis is more common among psoriasis patients with PsA than patients without PsA. *(Haroon 2013)*
- Patients with PsA and psoriasis tend to be heavier than unaffected individuals and patients with rheumatoid arthritis. *(Bhole 2012)*
- Obesity has been found to predict worse outcome and poor response to treatment in patients with psoriasis and PsA. *(Eder 2014)*
- Both psoriasis and PsA, similar to other systemic inflammatory conditions, were linked to an increased risk of developing cardiovascular diseases. *(Husted 2011)*
- Depression and anxiety are estimated to affect more than 30 percent of psoriasis patients.
 - Low self-esteem, social anxiety, embarrassment due to disease stigmas or absence from work due to painful arthritis may partly explain the psychosocial impact of psoriasis. *(Dowlathshahi 2014)*
- Depression or insomnia affects between 20 to 50 percent of patients with psoriasis or PsA. *(Fleming 2015)*
- Roughly two-thirds of people with psoriasis and/or PsA say their disease makes them feel angry, frustrated and/or helpless. *(Martinez-Garcia 2014)*
- More than half say psoriasis interferes with their ability to enjoy life. *(Martinez Garcia 2014)*
- Nearly 30 percent of people with psoriasis and/or PsA suffer from depression.
 - About 88 percent of family members report the same levels of depression and anxiety as those with psoriasis. *(Martinez Garcia 2014)*

- According to a 2014 study, 55 percent of patients with moderate-to-severe psoriasis, and 41 percent of patients with psoriatic arthritis, are not being treated to the established standards of care. *(Lebwohl 2014)*
- Patients with PsA who did not seek treatment in the previous 12 months said they did not think it would help, suggesting that education about the availability of effective treatments is needed. *(Kavanaugh 2016)*
- No curative treatments exist for this disease, but current treatments (particularly with biological drugs) may significantly reduce symptoms, improve joint function and prevent future complications.
 - The main goals of treatment are to achieve clinical remission, inhibit or prevent structural joint damage, and improve patients' quality of life. *(Löfendahl 2016)*

Economic Burdens

- A 2013 study found that although roughly 91 percent of patients with psoriasis or psoriatic arthritis were covered by insurance, the majority spent more than \$2,500 per year in out-of-pocket costs for their disease. *(Bhutani 2013)*
- Psoriatic disease is an expensive condition: The economic burden of psoriatic disease is up to \$135 billion a year. *(Brezinski 2015)*

**Most people with
Psoriatic Arthritis
(60 to 70%)
are diagnosed with
psoriasis first.**

(Kerschbaumer 2016)





IN THE U.S., PSORIASIS
REMAINS A COMMON,
IMMUNE-MEDIATED
DISEASE, AFFECTING
7.4 MILLION ADULTS.

(Rachakonda 2014)



Section 4:

Juvenile Arthritis

What is Juvenile Arthritis?

Juvenile arthritis (JA), also known as pediatric rheumatic disease, is an umbrella term used to describe the many autoimmune and inflammatory conditions or pediatric rheumatic diseases that can develop in children under the age of 16.

Nearly 300,000 children in the U.S. have some form of arthritis – more children than those who face cystic fibrosis¹, juvenile diabetes² and leukemia^{3,4}, combined.

Although the various types of juvenile arthritis share many common symptoms, like pain, joint swelling, redness and warmth, each type of JA is distinct and has its own special concerns and symptoms.

Some types of JA affect the musculoskeletal system, but joint symptoms may be minor or nonexistent. Juvenile arthritis can also involve the eyes, skin, muscles and gastrointestinal tract.

While it's difficult for kids to deal with the health challenges of their disease, they are empowering themselves by making healthier life choices. According to a 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation, 89 percent of these patients have started eating more healthfully to improve their arthritis health.

¹30,000 in U.S. with CF. Cystic Fibrosis Foundation (CFF). What Is CF? 2019. Accessed on 1.7.19 at <https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/>

²193,000 youth with diabetes in U.S. under age 20. American Diabetes Association. Statistics About Diabetes: Diabetes in Youth. 2019. Accessed on 1.7.19 at <http://www.diabetes.org/diabetes-basics/statistics/>

³About 15,780 children under age 20 are diagnosed with cancer in the U.S. each year. American Childhood Cancer Organization. US Childhood Cancer Statistics. 2019. Accessed on 1.7.19 at <https://www.acco.org/us-childhood-cancer-statistics/>

⁴Leukemia is the most common form of cancer in children and teens, accounting for 1 in 3 cancers. American Cancer Society. What are the key statistics for childhood leukemia? 2019. Accessed on 1.7.19 at <https://www.cancer.org/cancer/leukemia-in-children/about/key-statistics.html>



Common Forms of Juvenile Arthritis (JA)

Juvenile Idiopathic Arthritis (JIA). Considered the most common form of childhood arthritis, JIA includes six subtypes.

Juvenile-onset Systemic Lupus Erythematosus (SLE or Lupus). Lupus can affect nearly every organ system in the body, including the skin, joints, kidneys, heart, lungs and central nervous system.

Juvenile-onset Scleroderma. Scleroderma, which literally means “hard skin,” describes a group of conditions that causes the skin to tighten and harden. It is the third most frequent childhood rheumatic condition after JIA and systemic lupus erythematosus.

Juvenile Myositis (JM). JM, including juvenile dermatomyositis (JDM) and juvenile polymyositis (JPM), is a group of rare, life-threatening autoimmune diseases in which the body’s immune system attacks its own cells and tissues. Weak muscles, with or without skin rash, are the main symptoms of this disease.

Juvenile-onset Fibromyalgia. This disease can occur at any age, but is seen more often in girls and women, in people with a family history of fibromyalgia and/or in people with a rheumatic disease (like rheumatoid arthritis or lupus).



The Soler family, (Robin) JA Mom: “I Know Just Enough to Know I Don’t Know Enough.”

Among patient partners who reviewed *Arthritis by the Numbers* – a collection of verified arthritis facts and figures – was the Soler family of Georgia. Robin Soler has been active with the Arthritis Foundation ever since her younger daughter, Isabela, was diagnosed with juvenile idiopathic arthritis (JIA). At the time she was one of the youngest children in the state to be diagnosed with JIA at just 12 months old.

Over the past 15 years, mother and daughter have seen about 50 different doctors and scores of other medical experts. Isabela has taken at least 20 different types of prescription drugs – consuming more than 15,000 pills in her lifetime, not including antibiotics and other normal childhood drugs. She has missed countless parties and playdates, and one recent semester had to skip 7th period 21 times for doctor’s appointments.



Isabela’s mother, Robin, is a developmental psychologist and senior scientist at the Centers for Disease Control and Prevention in Atlanta. Robin has had her own personal experience with arthritis, diagnosed with fibromyalgia when she was 26, though her chronic pain goes back to her mid-teens.

After reviewing arthritis statistics we’ve collected, Robin’s main takeaway: “I am happy to know there is information out there, but I’m concerned about the pictures the numbers paint for parents. We and our children need to be hopeful.”

Grim Picture Can Be Better

Robin says the evidence on children with arthritis is sad, dismal and frustrating because the disease manifests itself in so many ways. “Are common solutions possible for the masses?” she wonders. “Or maybe each child is so unique and the quest for a more common solution is impossible. I don’t know. I know just enough to know I don’t know enough.”

“As a scientist,” Robin continues, “I think we need a comprehensive science agenda to pull together what we know, what we need to know and what we need to know first. Then we need to translate that for parents in a compassionate and responsible way.”

Currently, Isabela, now 16, copes with several conditions: polyarticular arthritis, fibromyalgia, uveitis in medicated remission, amplified pain syndrome, clinical depression, generalized anxiety disorder and chronic fatigue. She says she doesn’t remember not having arthritis. “I’ve had to form my day around arthritis,” Isabela says. “I’ve had to go on many medications, each with their own side effects and problems. I’ve had to try different diets. I try to push through at school. I already miss school enough for doctor’s appointments. If I left school each time I was in pain, then I would never be at school.”

Her older sister, Elena, 20, remembers watching Isabela drag herself around the floor because she couldn’t crawl or walk. “My sister’s diagnosis has been followed by countless pills, shots and blood tests,” says Elena. “Bela is my inspiration. Even before she could walk, she was a fighter. She’s my hero and my reason to be inspired.”





IN MANY CHILDREN,
JUVENILE IDIOPATHIC
ARTHRITIS IS A LIFE-LONG
ILLNESS WITH A HIGH RISK OF
DISEASE- AND TREATMENT-
RELATED MORBIDITY.

(Guzman 2014)



Juvenile Idiopathic Arthritis (JIA)

Juvenile idiopathic arthritis (JIA) has replaced the older terms juvenile rheumatoid arthritis (JRA, used in the U.S) and juvenile chronic arthritis (JCA, used in Europe). However, JIA is more inclusive than the older terms – it includes what was previously called JRA or JCA and other forms of “idiopathic” forms of childhood arthritis.

There are several JIA categories:

Systemic JIA (formerly called Still’s disease) causes inflammation in one or more joints and is often accompanied by a high spiking fever that lasts at least two weeks and a skin rash. About 10 percent of children with JIA will have this form.

Oligoarticular JIA causes arthritis in four or fewer joints, typically the large ones (knees, ankles and elbows). Children with this type of JIA are more likely to get uveitis (chronic eye inflammation) than those in the other categories.

- Persistent oligoarticular JIA – when four or fewer joints are affected for longer than six months
- Extended oligoarticular JIA – when five or more joints are affected within six months of symptoms beginning

Polyarticular JIA causes inflammation in five or more joints, often the small joints of the fingers and hands, but any joint can be affected, including weight-bearing joints and the jaw. About 25 percent of children with JIA will have this form. This category most closely resembles adult rheumatoid arthritis.

- Seropositive (RF) polyarticular JIA
- Seronegative (RF) polyarticular JIA

Juvenile psoriatic arthritis involves arthritis that usually occurs in combination with a skin disorder called psoriasis. The psoriasis may begin many years before any joint symptoms become apparent.

Enthesitis-related JIA is a separate category of JIA. It can be characterized by enthesitis, which is tenderness where the bone meets a tendon, ligament or other connective tissue.

- The tenderness may be associated with joint inflammation of arthritis and most often affects the hips, knees and feet.
- It can also occur without tenderness. In addition, this form of arthritis may be characterized by inflammation in the sacroiliac joints and other spine joints. This form is sometimes called spondyloarthritis or ankylosing spondyloarthritis.
- Patients with this form of arthritis may be positive for a blood test called HLA-B27.
- Some patients may also develop acute uveitis.

Undifferentiated arthritis describes juvenile arthritis that does not fit into any of the other types, or involves symptoms spanning two or more subtypes.

Prevalence

- More girls than boys are affected by juvenile idiopathic arthritis (JIA). (Harrold 2013)

- Data from family and twin studies suggest that susceptibility to JIA may be inherited.

- While siblings of JIA patients are more likely than the general population to develop JIA, the overall risk for these siblings to develop JIA is low. (Pralhad 2004)

- The girl-to-boy ratios of children affected range from 2:1 to 3:1, depending on the JIA category, age of onset and study population. (Grom 2018)

- The disorder has been identified all over the world in nearly all races and ethnicities, with an average prevalence rate of one to two per 1,000 children. (Gabriel 2009)

- JIA appears to be more common in Caucasian populations and less common in African-American and Asian populations in the U.S. (Grom 2018)

Human and Economic Burdens

Health Burdens

- A lot is unknown about the health burdens of JIA. Doctors are actively researching this to better understand how the disease impacts daily life and how best to support patients with the disease.
- Patients, parents and health care providers may use different criteria to determine if a disease is in remission.
 - Patients and parents feel the disease is in remission if patients have no pain (or less or tolerable pain), lack of stiffness (especially in the morning), no swelling, the ability to participate in activities, better sleep, more energy and feeling more capable or independent.
 - Doctors use joint examination, blood tests, feedback from the patient about pain and emotions, visual examinations, physical examinations and imaging (MRI) to determine disease remission. *(Morgan 2017)*
- Many children with JIA managed with contemporary treatments attain inactive disease within two years of diagnosis and some can discontinue treatment.
 - The probability of attaining remission within five years of diagnosis is about 50 percent, except for children with polyarthritis. *(Guzman 2014)*
- Nearly half of children with JIA have recurrent or ongoing disease activity on entry into adulthood. This includes:
 - active arthritis
 - progressive joint damage
 - continued exposure to chronic arthritis treatments
 - decreased health-related quality of life *(Weitzman 2018)*
- Methotrexate is an effective, relatively safe and low-cost treatment for children with JIA, but its use is often limited by significant nausea. *(Falvey 2017)*
- Among those taking methotrexate, a greater proportion of girls compared to boys reported symptoms of intolerance. *(Weitzman 2018)*
- Juvenile idiopathic arthritis-associated uveitis (JIA-U) can lead to ocular complications and permanent vision loss.
 - About 10 to 25 percent of children in the U.S. with JIA develop uveitis within the first four years of their arthritis diagnosis. *(Saurenmann 2007)*
- Patients with JIA have a poorer health-related quality of life (HRQL) compared to healthy peers in physical health, followed by the psychosocial domain.
 - The areas of HRQL most affected by juvenile idiopathic arthritis are:
 - o global health
 - o physical functioning
 - o role social limitation (physical)
 - o bodily pain/discomfort *(Oliveira 2007)*
- Health-related quality of life (HRQOL) in children who are newly diagnosed with juvenile idiopathic arthritis can vary, even with excellent symptom control. Strong predictors of HRQOL include:
 - the child's perception of social support
 - perceived difficulty with their treatment regimen
 - missed school *(Seid 2014)*
- Fatigue is common in patients with JIA, even when they reach adulthood.
 - Fatigue is significantly more common in patients with JIA compared to the general population. *(Armbrust 2016)*

JIA-ASSOCIATED UVEITIS

can lead to

Ocular Complications and Permanent Vision Loss.

(Saurenmann 2007)





- The consequences of JIA-induced fatigue can be major, as they hamper children's performance at school, social life, sports and hobbies. (Eyckmans 2011)

Mental Health Impact

- There are higher rates of depression in children with juvenile idiopathic arthritis (JIA) as compared to those without, but no difference when adults. (Krause 2016)
- The increased length of illness was linked with a higher percentage of cases with psychiatric disorders. (Mullick 2005)
- The presence of psychiatric disorders was related to considerable difficulties with learning, peer relationships and leisure activities.
 - This suggests that early recognition of psychiatric illness and management might improve the outcome in children with JIA. (Mullick 2005)
- Clinical classification of disease activity and severity is not directly linked to depression and trait-anxiety in children with JIA.
 - Self-efficacy corresponds with less pain and somatic complaints. (Vuorimaa 2008)

School and Social Impact

Adolescents with juvenile idiopathic arthritis (JIA) spent a greater percentage of time in bed and less time in moderate to vigorous physical activity.

- Only 23 percent of JIA patients meet public health guidelines on physical activity, compared with 66 percent in healthy peers. (Lelieveld 2008)

School functioning among adolescents with primary pain conditions (unrelated to a specific disease) and adolescents with JIA have:

- poorer school functioning and school quality of life
- more school days missed
- more visits to school nurses than healthy adolescents

(Agoston 2016)

- School function scores were not accounted for by pain intensity, pain frequency or time since pain onset.
 - However, pain intensity did emerge as a predictor of school-related quality of life. (Agoston 2016)

- Despite health challenges, young adults with JIA and healthy peers are comparable in terms of family background, scholastic and occupational self-concept, and academic competence. (Gerhardt 2008)
- The percentage of high school graduates and those working, as well as those planning for further studies or seeking employment, are equivalent in young adults with JIA and healthy peers. (Gerhardt 2008)
- JIA disease subtype, severity at presentation and time elapsed are not associated with educational and occupational accomplishment. (Gerhardt 2008)
- Despite JIA and the different associated challenges, young adults are similar to their healthy peers as they transition to adulthood. (Gerhardt 2008)

Economic Burdens

- A child with juvenile idiopathic arthritis (JIA) may incur high medical costs due to frequent visits to physicians and therapists to manage the disease. (Bernatsky 2007)
- There is higher inpatient health care utilization in children with JIA compared to those without it.
 - There is higher inpatient health care utilization for JIA due to joint surgery, nonjoint surgery and hospitalizations. (Krause 2016)
- Between 2000 and 2009, parents who had a child with JIA lost an average of US\$4,589.37 due to missed work compared to US\$2,986.08 for parents who had no children with JIA. (Kuhlmann 2016)



- Fifty-three percent of parents in JIA cases reported an increase in the number of missed work hours for the period covering the year before and the year after their child's index diagnosis.

- Parents of a child with JIA were 2.78 times more likely to report work-time loss than parents having no children with JIA.

- Parents of children without JIA were 64 percent less likely to experience work-time loss than parents with a child with JIA.

- Only 32 percent of parents of children without JIA reported a work-time loss. (Rasu 2015)

- A 2015 study in Europe showed a remarkable increase in annual health care costs for JIA patients due to the inclusion of nonprofessional caregiver costs, a wider use of biologics and longer hospital stays. (Kuhlmann 2016)

ONLY 23 PERCENT
OF JIA PATIENTS
MEET PUBLIC
HEALTH
GUIDELINES ON
PHYSICAL ACTIVITY,
COMPARED WITH
66 PERCENT IN
HEALTHY PEERS.

(Lelieveld 2008)



IT HAS BEEN FOUND THAT THERE ARE
HIGHER RATES OF DEPRESSION IN
CHILDREN WITH JUVENILE IDIOPATHIC
ARTHRITIS AS COMPARED TO THOSE
WITHOUT, BUT NO DIFFERENCE
WHEN ADULTS.

(Krause 2016)



Juvenile-onset Systemic Lupus Erythematosus (Lupus)

Lupus is an autoimmune disease. In autoimmune diseases, the immune system turns against the body for unknown reasons. Lupus can affect nearly every organ system in the body, including the skin, joints, kidneys, heart, lungs and central nervous system. Most often when people speak of childhood lupus, they are referring to systemic lupus erythematosus (SLE).

SLE is often characterized by periods of illness and remission. There are many symptoms associated with lupus. It can affect the joints, skin, brain, lungs, kidneys and blood vessels. It affects every organ system in different ways. Children and teens with SLE may have fatigue, pain or swelling in joints, skin rashes, fevers, hair loss, mouth sores or skin color changes due to cold temperatures (Raynaud's phenomenon). Fatigue is one of the most prominent and life-affecting symptoms. Joint pain, another prominent symptom, is what most commonly initiates the first doctor's visit.

Prevalence

- About 15 to 20 percent of all systemic lupus erythematosus (SLE) cases develop before the age of 18. *(Weiss 2012)*
- About three to nine cases of juvenile-onset SLE are diagnosed for every 100,000 children. *(Kamphuis 2010)*
- Juvenile-onset SLE usually begins around puberty. *(Gheith 2017)*
- Juvenile-onset SLE is very rare before the age of 5. *(Cabral 2013)*
- Although uncommon, juvenile-onset SLE has been diagnosed in children younger than 2 years old. *(Pluchinotta 2007)*
- The girl to boy patient ratio with this disease changes with age:
 - During the first decade of life, there are four girls diagnosed for every three boys.
 - During the second decade of life, four girls are diagnosed for every one boy. *(Mina 2010)*
- Juvenile-onset SLE is diagnosed more often in Asian, African-American, Hispanic and Native American children compared to white children. *(Hiraki 2009)*
 - In white children, juvenile-onset SLE is 10 to 15 times less common than juvenile idiopathic arthritis (JIA) and Type 1 diabetes. *(Malleson 1996)*
 - In Asian children, juvenile-onset SLE is as common as JIA. *(Huang 2004)*

Health Burdens

- Diagnosis of systemic lupus erythematosus (SLE) in adolescence is not always obvious since the clinical and blood test results commonly seen in these patients may mimic other medical conditions frequently seen in this age group. *(Amaral 2014)*
- The diagnosis should be made by a clinician with expertise in rheumatology. Lupus can affect different body organs, and the organs affected can differ from patient to patient. Children with lupus often have one or more of the following symptoms:
 - fever, fatigue, weight loss
 - arthritis or joint pain
 - "butterfly rash" on the cheeks and bridge of nose, or other rashes
 - sores in the mouth or nose
 - seizures or other nervous system problems (depression, psychosis)
 - fluid around the heart or lungs
 - kidney problems (abnormal urine tests)
 - problems with the blood: anemia or easy bruising, low platelets, low white blood cell numbers
 - immune system problems (specific abnormal antibodies) *(ACR 2018)*
- Pediatric patients with SLE typically have more severe disease than their adult counterparts. *(Klein-Gitelman 2003)*
 - They often have serious organ damage (like kidneys) at presentation and over the course of the disease. *(Mina 2010)*
 - They have increased need for longer-term immunosuppressive treatment. *(Mina 2010)*

Skin Involvement

- The malar, or butterfly, rash is seen in 60 to 90 percent of children with systemic lupus erythematosus.
 - The rash often extends over the nose and affects the chin and ears.
 - The rash is triggered by the sun ("photosensitive") in more than a third of patients.
 - Sun exposure may cause a systemic flare of lupus affecting other organs. *(Levy 2012)*

Joint Involvement

- Arthritis occurs in about 60 to 90 percent of patients with juvenile SLE.
 - The arthritis is like that seen in juvenile idiopathic arthritis.
- However, the arthritis is almost always nonerosive and nondeforming. *(Levy 2012)*

Kidney Involvement

- Kidney disease (nephritis) occurs in over 40 percent of all juvenile SLE patients (Levy 2012, Amaral 2014), with more than 90 percent of those developing the disease within the first two years after diagnosis. *(Hiraki 2008)*
- Kidney involvement in this disease increases the risk of several problems, including:
 - kidney dysfunction and possible failure, requiring dialysis or transplantation
 - high blood pressure affecting the cardiovascular system and brain (like stroke and heart disease)
 - adverse effects on the bones during growth and development
 - need for high-dose steroids and other immunosuppression *(Wenderfer 2017)*
- Juvenile-onset SLE is associated with a greater risk of developing nephritis than adults who develop lupus. *(Mina 2010)*
- Since 1990, about 92 to 95 percent of patients with SLE survive at least 10 years after diagnosis.
 - About 89 to 90 percent of these patients with nephritis survive at least 10 years after diagnosis. *(Wenderfer 2017)*

Nervous System Involvement

- Up to 65 percent of these patients develop one or more of the distinct neuropsychiatric lupus (NPSLE) syndromes that involve the central and peripheral nervous systems. There are 19 NPSLE syndromes defined by the American College of Rheumatology.
 - Up to 85 percent of these patients will develop NPSLE within the first two years of diagnosis. *(Benseler 2007)*
- Among the most common forms of NPSLE seen in these patients:
 - Headache can be mild to debilitating.
 - Mood disorder ranges from mild to major depression (depression may be normal and appropriate reaction for an adolescent dealing with chronic disease).
 - Cognitive dysfunction (declining school performance, difficulties with memory and concentration) is observed in more than a third of asymptomatic patients.
 - Psychosis includes visual and auditory hallucinations.
 - Seizures are frequently seen with other NPSLE syndromes, but rarely as isolated. *(Levy 2012)*
 - Brain vascular disease may cause stroke due to blood clotting.

Immune System Impact

- These patients in general are immunocompromised due to immune dysfunction of the disease and to frequent use of high-dose corticosteroids and other immunosuppressive treatment. *(Levi 2012)*
- Vaccination recommendations:
 - Killed and recombinant forms of vaccines are safe and recommended at their usual administration time.
 - Yearly influenza vaccine (killed injectable, NOT live, attenuated nasal mist) is strongly recommended.
 - Meningococcal and pneumococcal vaccination is recommended.
 - For those who have not had chickenpox or prior vaccination, live, attenuated vaccine is recommended at least four weeks before the start of immunosuppression.
 - No live, attenuated vaccines should be given to these patients while receiving systemic immunosuppressive drugs. *(Heijstek 2011)*

Mental Health Impact

- Mental health statistics for children and teens with systemic lupus erythematosus (SLE):
 - One in three young people with lupus experience symptoms of depression and/or anxiety.
 - One in six young people with lupus experience thoughts of suicide, which is higher than their healthy peers.
 - Up to 75 percent of youth with lupus have not had a mental health evaluation. *(Knight 2017)*
- The increased prevalence of depression and anxiety in juvenile SLE is complex and related to several factors:
 - psychological stress of dealing with chronic illness during adolescence
 - steroid effects on the CNS
 - steroid effects on body changes (like increased weight gain, acne)
 - heredity and environmental factors *(Knight 2014)*
- Depression and anxiety are shown to result in poorer disease control, quality of life, school performance and transition to adult care. *(Knight 2014)*
- Mild symptoms of depression may be overlooked as part of normal adolescent development, but persistent mild or “subthreshold” depression symptoms are a predictor of development of major depression and suicidal behavior in later adulthood and should be evaluated. *(Knight 2014)*
- Patients with depression symptoms visit their primary care doctors about 60 percent less frequently than those without symptoms.
 - This may suggest that depressed patients and their potentially depressed caregivers may exhibit negative coping styles and social withdrawal. *(Knight 2014)*
- Despite indications for a need, there are no existing guidelines or standard practices for mental health screening and intervention for depression, anxiety and suicidal ideation for pediatric systemic lupus erythematosus in the context of pediatric rheumatology care. *(Knight 2014)*

School and Social Impact

- Neurocognitive impairment (NCI) is one of the 19 neuropsychiatric syndromes of systemic lupus erythematosus (SLE) defined by the American College of Rheumatology.
 - This may have a substantial impact on learning, academic and vocational success in children and adolescents.
 - The prevalence of NCI in this population ranges from 20 to 95 percent, depending on the tests used for diagnosis. *(Williams 2011)*
- Juvenile SLE patients are affected in areas of executive functioning (mental flexibility), psychomotor (physical skills that require mental coordination) and fine-motor speed. *(Williams 2011)*
- More than a third of these patients report that the disease has negatively interfered with their education. *(Levy 2012)*
- While children and teens with SLE may demonstrate poorer academic performance than healthy peers, the poorer performance is more closely linked to missed school time due to disease severity and treatment intensity. *(Zelko 2012)*

One in three
young people
with **LUPUS**
experience symptoms of depression and/or anxiety.



(Knight 2017)

Juvenile-onset Scleroderma

Scleroderma, which literally means “hard skin,” describes a group of conditions that causes the skin to tighten and harden. There are two basic forms:

- **Localized scleroderma.** It is primarily a skin disease and is the type seen more commonly in children. Localized juvenile scleroderma can damage the skin, muscle, bones and joints, depending on the type. It is unlikely to cause damage to internal organs.
- **Systemic sclerosis.** This type affects the entire body. It causes internal organ damage and may be severe.

Juvenile-onset scleroderma can occur at any age and in any race, but it is more common in girls. It is a rare disease. However, it is the third most frequent rheumatic condition in childhood after juvenile idiopathic arthritis and systemic lupus erythematosus (Zulian 2013).

Prevalence

- It is estimated that 10 percent of all patients with scleroderma develop the disease before the age of 8. (Zulian 2013)
- Juvenile scleroderma is rare.
 - However, it is the third most frequent childhood rheumatic condition after juvenile idiopathic arthritis and systemic lupus erythematosus. (Zulian 2013)
- The clinical presentation of scleroderma differs between adults and children.
 - Children typically have either juvenile localized scleroderma or juvenile systemic sclerosis. (Adrovic 2015)
- Juvenile localized scleroderma is the most frequent form of scleroderma in childhood, but it can occasionally progress into the systemic form. (Zulian 2013)
 - About one to three new cases of localized scleroderma are diagnosed per 100,000 children per year. (Peterson 1997)
 - Localized scleroderma (LS) has several subtypes. Linear scleroderma, the most common pediatric subtype, occurs in about 50 to 60 percent of children with LS. (Zulian 2006)
- Less than 5 percent of all juvenile-onset scleroderma patients have systemic sclerosis. (Torok 2012)
 - About one new case of systemic sclerosis is diagnosed per 100,000 children per year. (Pelkonen 1994)
 - About four times as many girls are diagnosed with juvenile-onset systemic sclerosis than boys. (Scalapino 2006)

Health Burdens

Juvenile Localized Scleroderma

- About 50 percent of children with linear scleroderma of the extremities have orthopedic complications.
- About 40 percent of children with linear scleroderma of the head have neurologic or ocular symptoms.
- About 2.1 percent of children with linear scleroderma have Raynaud’s syndrome.
- Less than 2 percent of children with linear scleroderma have gastrointestinal, respiratory or renal symptoms. (Zulian 2005)

Although rare,
**JUVENILE
SCLERODERMA**
is the **third most**
frequent childhood
rheumatic condition.

(Zulian 2013)





Juvenile Systemic Scleroderma

- Internal organ involvement in pediatric systemic sclerosis patients (in decreasing frequency) include:

- Gastrointestinal – occurs in about half of pediatric systemic sclerosis patients
- pulmonary (lungs)
- musculoskeletal
- cardiac
- renal (kidney)
- neurological systems *(Scalapino 2006)*

- Compared to adult-onset systemic sclerosis, muscle and skeletal involvement is more common in pediatric systemic sclerosis.

- About 30 to 50 percent of pediatric systemic sclerosis patients experience inflammatory arthritis. *(Torok 2012)*

- Despite all the potential organ involvement in systemic sclerosis, children have a more favorable long-term prognosis due to a lower frequency of severe organ involvement. *(Torok 2012)*

- Although infrequent, cardiac involvement is the major cause of scleroderma-related deaths in children with systemic sclerosis. *(Torok 2012)*

- Annual cardiovascular screening for patients with juvenile sclerosis is important to reduce the cardiovascular and pulmonary complications of pulmonary arterial hypertension.

(Adrovic 2015)

- Pulmonary involvement in pediatric systemic sclerosis patients ranges from 30 to 70 percent, and includes:

- interstitial lung disease
- pulmonary arterial hypertension
- abnormal lung function tests *(Panigada 2009)*

- Pulmonary arterial hypertension is estimated to occur in about 7 percent of children with systemic scleroderma.

(Martini 2006)

Mild renal (kidney) problems are not uncommon in systemic sclerosis.

- Scleroderma-related renal crisis is less common in children; it occurs in less than 15 percent of pediatric patients. *(Torok 2012)*

BETWEEN 30 TO 50 PERCENT OF
CHILDREN WITH SYSTEMIC SCLEROSIS
HAVE INFLAMMATORY ARTHRITIS.

(Zulian 2005)

Juvenile Myositis (JM)

Juvenile Dermatomyositis (JDM) and Juvenile Polymyositis (JPM) are two different forms of idiopathic inflammatory myopathy, which together in children is called Juvenile Myositis (JM). While this disease can occur at any age, it usually appears in children and adolescents between the ages of 5 and 15 and in adults between the ages of 40 and 60.

JM involves weakness of the muscles closest to the center of the body like the muscles of the hips and thighs, upper arms, and neck. People with this disease may find it difficult to perform everyday tasks like climbing stairs, getting out of a chair, or lifting items above their head. In some cases, it may make swallowing or breathing difficult.

Both JDM and JPM cause weakness in muscle used for movement. However, in JDM a reddish or purplish skin rash on the eyelids and knuckles develops. There is no rash with JPM.

In JM, the muscle weakness develops gradually over a period of weeks to months or even years. Other symptoms include joint pain and general tiredness (fatigue). All age and ethnic groups are affected. Roughly 1 in 5 children also has joint symptoms, but they are likely to be mild. Remission is possible, but a minority of children with JDM may have a more chronic disease course.

Prevalence

- In childhood, dermatomyositis occurs far more frequently than polymyositis, whereas in adults the ratio is more equal. *(Rider 2009)*
- Juvenile polymyositis occurs less frequently and accounts for only 3 to 6 percent of childhood idiopathic inflammatory myopathies. *(McCann 2006)*
- Juvenile dermatomyositis (JDM) is the most common idiopathic inflammatory myopathy of childhood, accounting for approximately 85 percent of cases. *(McCann 2006)*
- JDM is found in patients of all ethnic and racial backgrounds – its distribution appears to be comparable population demographics in the U.S. *(Robinson 2014)*
- Girls are up to five times more likely than boys to be affected by JDM. *(Symmons 1995)*
- JDM occurs in two to four cases per 1 million children per year in the U.S.
 - The average JDM disease onset is age 7. *(Mendez 2003)*

Health Burdens

Juvenile Myositis

- Despite considerable advances in the management of juvenile myositis (JM), the conditions are still associated with significant morbidity and mortality, representing a major long-term medical, social and economic burden on patients, their families and health care systems. *(Ravelli 2010)*
- In JM patients followed between 1993 and 2002, damage was present in 79 percent of the patients 82 months after diagnosis, which most commonly included joint contractures, weakness and cutaneous scarring. *(Rider 2009)*
- Reduced heart rate variability in JM patients may be associated with elevated inflammatory markers, active disease and decreased heart muscle function. *(Barth 2016)*
- JM patients may be at increased risk of cardiovascular disease in adult life. *(Schwartz 2011)*

Juvenile Dermatomyositis

- Juvenile dermatomyositis (JDM) is:
 - Characterized by muscle weakness and a characteristic skin rash;
 - But other organ systems, such as the heart, lungs, joints and gastrointestinal tract, may also be affected. *(Pachman 1990)*



- Due to improvements in treatments, 99 percent of patients with JDM are expected to survive. *(Ravelli 2010)*
- Aggressive treatment of JDM, aimed at achieving rapid, complete control of muscle weakness and inflammation, appears to improve outcomes and reduce disease-related complications.
 - Medication-free remission was attained within an average of 38 months in more than one-half of the children (28 of 49) whose disease was treated with this approach. *(Kim 2009)*
- Up to 30 percent of JDM patients may develop:
 - calcinosis, which is associated with worse functional outcomes
 - skin or gastrointestinal ulceration, which is associated with a severe course of illness *(Huber 2000)*
- Minority race and lower family income was found to be associated with worse morbidity and outcomes in patients with JDM in a group of North American children.
 - Minority children had worse physical function, more disease activity and lower quality of life scores.
 - Patients with lower family income have worse physical function, more disease activity, more weakness and lower quality of life scores.
 - African-American patients were more likely to have calcinosis. *(Phillipi 2017)*

GIRLS ARE UP TO
5 TIMES MORE
LIKELY THAN BOYS
TO BE AFFECTED
BY JUVENILE
DERMATOMYOSITIS.

(Symmons 1995)

Juvenile-onset Fibromyalgia

Fibromyalgia is often thought of as a condition that affects adults, but it can occur in kids, too. No matter what age it occurs, fibromyalgia can cause widespread musculoskeletal pain accompanied by fatigue, sleep and mood issues. Scientists are not sure what causes fibromyalgia, but it is seen more often in girls and women, in people with a family history of fibromyalgia, and/or in people with a rheumatic disease (like rheumatoid arthritis or lupus). Sometimes, symptoms gradually accumulate over time with no single triggering event. Sometimes, symptoms begin after a physical trauma, surgery, infection or significant psychological stress.

In kids with fibromyalgia, symptoms may include:

- **Widespread, diffuse pain.** This is often described as a constant dull ache that has lasted for at least three months. To be considered widespread, the pain must occur above and below the waist on both sides of the body.
- **Frequent headaches.** These occur in most patients with fibromyalgia.
- **Continuing sleep disturbances.** Despite complaints of severe fatigue, kids with fibromyalgia often take more than an hour to fall asleep. Many have difficulty staying asleep and wake up during the night.
- **Constant, unrelenting fatigue.** These kids often wake up tired, even after sleeping for long periods of time. Sleep is often disrupted by pain. Kids with fibromyalgia may also have other sleep disorders, like restless legs syndrome or sleep apnea.
- **Other problems.** Kids with fibromyalgia may also have pain or cramping in the lower abdomen, may feel like they have brain fog and experience depression and anxiety. (Mayo 2018)

Prevalence

- Fibromyalgia can develop at any age, including in childhood. (McBeth 2007)
- Juvenile-onset fibromyalgia (JFM) occurs most commonly in adolescent girls. (Yunus and Masi 1985 and Kashikar-Zuck 2014a)
- About 2 to 6 percent of school children are affected by JFM. (Kashikar-Zuck 2014a)
- About 7 to 15 percent of referrals to pediatric rheumatology clinics are due to JFM. (Kashikar-Zuck 2014a)
- Mothers of children with JFM are four times as likely to have fibromyalgia than mothers of healthy children. (Kashikar-Zuck 2008a)

Health Burdens

- Juvenile-onset fibromyalgia (JFM) is associated with considerable difficulty in physical, social and emotional functioning. (Flowers 2011)

- Early symptoms of JFM in children may be confused with growing pains.
 - Growing pains tend to occur in younger children (pre-teens), mainly at night.
 - JFM symptoms tend to occur during adolescence and are chronic throughout the day.
 - This uncertainty, combined with the fact that all symptoms of JFM don't appear at once, may delay diagnosis and appropriate treatments for two or more years. (Kashikar-Zuck 2014a)

Early symptoms of **JFM** in children may be **confused with growing pains.**

(Kashikar-Zuck 2014a)

- Studies in the 1990s in Europe suggested that about 70 percent of school-age children who had JFM symptoms no longer met the criteria for the disease after two years.

(Buskila 1995 and Kashikar-Zuck 2014a)

- More recent studies in the past decade show that most JFM patients seen in pediatric specialty care (>80 percent) continued to report pain and other disease-related symptoms (such as fatigue and sleep difficulty) into their early 20s.
 - Half of the most impaired patients had the most severe symptoms.
 - Persistence of this disease into early adulthood is associated with significant impairment of physical functioning, lower perceived health status and higher health care utilization.

(Kashikar-Zuck 2014a)

Mental Health Impact

- Depression, anxiety and attentional disorders are common mental health conditions in juvenile-onset fibromyalgia (JFM) patients. (Kashikar-Zuck 2008b)
- The lifetime prevalence of major depression is estimated to be 26 percent in children with JFM and 61.5 percent in adults with fibromyalgia. (Schaefer 2015)

Pain intensity and pain duration are not significantly related to school functioning.

(Zulian 2013)



- When compared to adults with fibromyalgia, adolescents with the disease had higher rates of current anxiety disorders.
 - By comparison, adolescents had lower rates of depressive disorders than adults. (Cunningham 2015)

School Impact

- School absenteeism is common, with adolescents missing an average of three school days per month, and several of them are unable to attend regular school at all (that is, they are home schooled) because of the symptoms of juvenile-onset fibromyalgia (JFM). (Kashikar-Zuck 2010)
 - JFM patients have been shown to be absent about three times more often than the average student (27 versus nine days). (Kashikar-Zuck 2008b)
 - Pain intensity and pain duration are not significantly related to school functioning. (Kashikar-Zuck 2010)
 - However, depression is significantly associated with impairment of school functioning, including school attendance.
 - School absenteeism is a risk factor for school dropout and multiple economic, marital, social and psychiatric problems in adulthood.

Social Impact

- Adolescents with juvenile-onset fibromyalgia (JFM) are seen by their classmates (and themselves) as being isolated, more emotionally sensitive than their healthy peers and have fewer friendships. (Kashikar-Zuck 2010)
- Adolescents with JFM are more likely to report childhood trauma (including physical or sexual abuse) than healthy peers. (Cunningham 2015 and Nelson 2017)
- Young adults with JFM are more likely to marry and have children at an early age, and less likely to attend college, than healthy peers. (Kashikar-Zuck 2014b)

Currently Recommended Treatments

- Early intervention for young people with juvenile-onset fibromyalgia (JFM) is important to avoid long-term negative effects on quality of life, mood and functioning into adult years.

(Kashikar-Zuck 2014a)



- Less invasive interventions are recommended for initial treatment and have been found to be effective in improving coping, daily functioning and mood.

- A randomized clinical trial showed that cognitive behavioral therapy is effective in reducing disability and reducing depressive symptoms in JFM.

(Kashikar-Zuck 2012)

- One study showed that mindfulness-based stress reduction (MBSR) was also useful in reducing JFM pain and disability. *(Ali 2017)*

- Multidisciplinary treatments, which include psychological coping-skills training and physical exercise, are recommended treatments for JFM.

(Weiss and Stinson 2018, Black and Kashikar-Zuck 2017)

- Newer studies show that specialized exercise programs tailored for patients with JFM are well tolerated and effective in reducing pain and improving function.

(Kashikar-Zuck 2012 and Kashikar-Zuck 2018)

- No randomized studies have shown the efficacy of complementary and alternative medicine treatment in JFM, although the use of adult data modified for children, for those therapies deemed safe, may be considered. *(Ali 2014)*

- These interventions include increased exercise, mind-body therapies (like yoga, tai chi, etc.), omega 3 fatty acid supplementation, and massage therapy.

(Ali 2014)

WHEN COMPARED TO ADULTS WITH FIBROMYALGIA, ADOLESCENTS WITH THE DISEASE HAD HIGHER RATES OF CURRENT ANXIETY DISORDERS.

(Cunningham 2015)

Section 5:

Gout

What is Gout?

Gout is not an autoimmune inflammatory disease. Gout is a form of metabolic inflammatory arthritis. Metabolic diseases occur when the body does not break down food (chemicals) in a normal way to produce energy on a cellular level. It is related to the types and amounts of food we eat and how our body processes (metabolizes) them. Gout develops in some people who have high levels of uric acid in the blood. Rich food and drink can contribute to the development of gout, but the real cause is how the body breaks down purines into uric acid.

If excess uric acid builds up, it can form needle-like crystals that cause pain in a joint. The joint pain can appear suddenly, with severe episodes of pain, tenderness, redness, warmth and swelling. The pain may last hours or weeks and make it difficult to perform daily activities.

Despite the pain and challenges gout causes patients, 95 percent of gout patients say there are things a person can do to make their arthritis better (source: 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation). Lifestyle factors, such as eating a rich diet high in certain high-purine foods (like red meats or shellfish), being overweight or obese and excessive alcohol use can, contribute to the development of gout.

The following facts describe some of the features common to gout.

Patient Partner's Words of Wisdom About Living With Gout & OA

Meet Craig Buhr, who is challenged by gout and OA. Following, in his own words, are his thoughts about the statistics he reviewed in *Arthritis by the Numbers* – and how they relate to him personally.

Question: How did you get involved with the Arthritis Foundation's mission to stop arthritis?

Craig: I first noticed joint pain when I was 42. I was diagnosed with osteoarthritis, having enlarged knuckles and other typical symptoms. I thought arthritis was just a part of aging. My pain intensified over the next years, causing difficulty in walking and maintaining an active work and home lifestyle. As a detail-oriented engineer, I did research to better understand this disease. I learned so much from the Arthritis Foundation's books, *Arthritis Today* magazine and information online.

Question: How do the statistics you reviewed apply to what you were going through?

Craig: There's a correlation between gout and OA, shown by comorbid biomarkers. I didn't know that before reading about it through the Arthritis Foundation. If I had, I would have posed more specific questions to my doctor earlier or modified my diet sooner as a preventive measure.

Question: What changes have you made in your life?

Craig: Excess weight has a severe and detrimental effect on joint longevity. I ramped up my cardio-based fast-walking, and cross-trained with weights on alternating days. I was able to lose 37 pounds in just over a year. I participated in the Arthritis Foundation's Jingle Bell Run for the first time and recorded my best overall personal pace. I've been able to contain my gout flares. Conquering OA, which is a sinister and progressive disease that slowly degenerates joints, has been more challenging. But wraps, braces and heating packs have helped.

Question: What's your advice to someone newly diagnosed with arthritis?

Craig: Equip yourself with knowledge from the Arthritis Foundation. Seek medical assistance promptly. Talk with others going through this. Adjust your lifestyle to mitigate the long-term impact of OA, gout and other joint diseases. Expect rough spots. Get some rest. Volunteer to help others dealing with this. Research is constantly learning more about these debilitating diseases, so keep the faith and take care.

Question: What would you like arthritis researchers and health care experts to focus on?

Craig: I'd like to learn more about when it might be appropriate to get a joint replacement. How long do I put up with discomfort and loss of mobility before I consider that? We all desire the best quality of life, whatever stage of life. We want to function and remain active members of society.



Prevalence

- Gout is one of the most common rheumatologic diseases and is the most common cause of inflammatory arthritis among adults in the U.S. (Khanna 2012)
- About 3.9 percent of adults, or 8.3 million individuals, have gout in the U.S. (Zhu 2011)
- There is a progressively greater prevalence of gout associated with higher weight. In the U.S., the prevalence of gout is:
 - 1-2 percent among people of normal weight
 - 3 percent among overweight people
 - 4-5 percent with Class 1 obesity
 - 5-7 percent with Class 2 or 3 obesity (Jurascheck 2013)
- Obesity is not only a risk factor for incident gout, but is also associated with an earlier age of gout onset. (McAdams 2011)
- In Western developed countries, contemporary prevalence of gout is:
 - 3 to 6 percent in men
 - 1 to 2 percent in women
 - Prevalence steadily increases with age, but plateaus after age 70 (Kuo 2015)
- The prevalence of gout increases with age and peaks at more than 12 percent in people more than 80 years old. (Zhu 2011)
- Men are nearly three times more likely to develop gout, compared with women, and black males are most commonly affected. (Wilson 2016)
- Gout is rarely seen in pre-menopausal women but can be found in postmenopausal women. (Sunkureddi 2006)
- Gout incidence increases with age in both men and women, with the most significant age-related increase noticed in postmenopausal women. (Wilson 2016)

Gout in Women

- The onset of gout occurs at a later age in women.
 - They are more likely to have comorbidities, such as hypertension or renal insufficiency.
 - They use diuretics more often. (Dirken-Heukensfeldt 2010)

- Because gout is a rare disease in women before menopause, and it can have an unusual way of manifesting itself, it is very important to recognize the symptoms.

- Health care providers should consider gout especially in postmenopausal female patients with hypertension, diuretic use, renal insufficiency and arthritis in one or more joints.
- Women may more often have other joints involved than just one toe, and their gout often recurs less than in men.

(Dirken-Heukensfeldt 2010)

Human and Economic Burdens

Health Burdens and Comorbidities

- Acute gout may be treated with nonsteroidal anti-inflammatory drugs, corticosteroids or colchicine. To reduce the likelihood of flares, patients should:
 - Limit consumption of certain purine-rich proteins (like red meat, wild game, organ meats and shellfish, and some large saltwater fish).
 - Avoid alcoholic drinks (especially beer).
 - Avoid beverages sweetened with high-fructose corn syrup.
 - Eat more vegetables and low-fat or nonfat dairy products.
 - o Eating purine-rich nuts, oatmeal, asparagus, legumes and mushrooms do not seem to increase risk of gout flares. (Hainer 2014)
- About 60 percent of patients experience a recurrent gout flare within one year of an initial event.
 - About 78 percent experience a recurrent flare within two years. (Brixner 2005)
- Advanced gout is associated with impaired mobility and reduced health-related quality of life, as well as an increased risk of all-cause mortality. (Dalbeth 2016)
- Gout is associated with increased risk of death, primarily due to cardiovascular disease. (Choi 2007)
- Pain associated with acute gout has been described as intolerable, resulting in a feeling of desperation for the attack to end and a sense of helplessness. (Lindsay 2011)
- Gout has a substantial comorbidity burden and is particularly interconnected with other diseases associated with hyperuricemia, such as diabetes, hypertension and obesity. (Karis 2014)

- The National Health and Nutrition Examination Survey data from 2007-2008 reported that among gout patients:
 - 74 percent had hypertension
 - 71 percent had stage two or greater chronic kidney disease
 - 53 percent were obese
 - 26 percent had diabetes
 - 14 percent have had myocardial infarction
 - 10 percent have had a stroke *(Dalbeth 2016)*
- Gout flares frequently result in patients being unable to bear weight and being bedbound for the duration of the acute attack.
 - Severe foot pain, impairment and disability were observed in a study among patients with acute gout. *(Rome 2012)*
- Patients with gout have higher-than-average medical costs and health care utilization than patients without gout. *(Jackson 2015)*
- While comorbid conditions may account for some of the elevated resource use among gout patients, gout-related health care utilization increases with the severity of gout. *(Singh 2011)*
- Nearly 8 percent of all emergency department visits for gout result in hospitalization, with a median inpatient stay approaching three days. *(Singh 2016)*
- From 1993 to 2009, the frequency of outpatient visits for gout increased three-fold, with the most significant increase after 2003. *(Krishnan 2013)*

Work/Employment Impact

- Poorly controlled gout leads to absences from work, health care use and reduced social participation. *(Khanna 2012)*
- The U.S. labor force consisted of 155 million persons in July 2012. If gout is present in 2 percent of workers (3.1 million persons), and each misses five days annually as a result of the disease, the yearly loss of wages/productivity amounts to:
 - \$833 per worker (based on 2010 data)
 - an overall loss of \$2.6 billion *(Wertheimer 2013)*
- Compared to workers without gouty arthritis, employees with this condition used significantly more sick leave, short-term disability and workers' compensation benefits. *(Brook 2006)*
- The number of workdays missed increases as the number of yearly gout flares increases. *(Lynch 2013)*

Medical/Cost Burden

- Increased costs of gout are generally associated with poorly controlled disease and are largely modifiable.
 - Gout is a metabolically-driven disease that can be fully controlled with proper treatment approaches.
 - Substantial resources could be spared by closing the gap between doctor recommendations and patient practices. *(Rai 2013)*
- Gout accounts for about 7 million doctor's visits in the U.S. at an annual cost of nearly \$1 billion. *(Li 2013)*
- From 2002 to 2008:
 - There were a total of 50.1 million gout-related ambulatory visits in the U.S.:
 - o an average of 7.2 million visits per year
 - o costing about \$1 billion annually *(Li 2013)*
- From 2006 to 2012:
 - The rate of emergency department visits for gout in adults:
 - o increased 14 percent, from 75.0 to 85.4 per 100,000
 - o increased 29 percent for those ages 45 to 54
 - Emergency department charges increased from \$156 million to \$281 million (an 80 percent increase). *(Jinno 2016)*
- From 2009 to 2012, the number and cost of emergency department (ED) visits with gout as the primary diagnosis rose.
 - In 2009, there were 180,789 ED visits, costing a total of \$195 million.
 - In 2010, there were 201,044 ED visits, costing \$239 million.
 - In 2012, there were 205,152 ED visits, costing \$287 million.
 - These accounted for 0.14 to 0.16 percent of all ED visits. *(Singh 2016)*
- In 2012, the combined estimate of annual direct and indirect costs of gout patient care totals more than \$6 billion. This included:
 - \$4 billion in direct costs
 - \$2.6 billion in indirect costs *(Wertheimer 2013)*



GOUT IS ONE OF THE MOST COMMON
RHEUMATOLOGY DISEASES AND IS
THE MOST COMMON CAUSE OF
INFLAMMATORY ARTHRITIS AMONG
ADULTS IN THE UNITED STATES.

(Khanna 2012)



Section 6:

Fibromyalgia

What is Fibromyalgia?

Fibromyalgia is a condition associated with widespread, amplified chronic pain, which is experienced in different parts of the body at different times. This, along with other symptoms, such as fatigue, nonrefreshed sleep, memory problems and mood changes, all strongly impact the quality of life for these patients. It is not a single disease, but a constellation of symptoms that can be managed.

Although fibromyalgia is not a form of arthritis, because it does not inflame or damage joints, it is considered an arthritis-related condition. It is often found as a comorbid condition in people who have different forms of arthritis, like osteoarthritis, rheumatoid arthritis, lupus and inflammatory bowel disease.

Fibromyalgia affects more than 3.7 million Americans. The majority are women between 40 and 75, but it also affects men, young women and children, especially adolescent females. It sometimes occurs in more than one member of the same family, suggesting that a predisposing gene may exist.

While the challenges of this disease are difficult to deal with, 92 percent of fibromyalgia patients say they actively seek out information on their illnesses

(source: 2016 Nielsen consumer needs survey conducted for the Arthritis Foundation).





PATIENTS HAVE CHARACTERIZED LIVING
WITH FIBROMYALGIA AS FEELING
INVISIBLE, BEING DOUBTED BY OTHERS
BECAUSE THE SYMPTOMS OF
FIBROMYALGIA ARE SUBJECTIVE AND
NOT SEEN BY OTHERS.

(Juuso 2011)



Prevalence

- Fibromyalgia is present in as much as 2 to 8 percent of the population, is characterized by widespread pain, and is often accompanied by fatigue, memory problems and sleep disturbances. (Clauw 2014)
- Fibromyalgia remains undiagnosed in three of four people with the disorder. (Clauw 2011)
- Based on newer diagnostic criteria, twice as many women are diagnosed with fibromyalgia than men, which contrasts the older 1990 criteria where the female-to-male ratio was 9:1. (Vincent 2013)
- The prevalence is similar in different countries, cultures and ethnic groups; there is no evidence that fibromyalgia has a higher prevalence in industrialized countries and cultures.
 - Fibromyalgia can develop at any age, including in childhood. (McBeth 2007)

Human and Economic Burdens

Disease Triggers

- Twin studies suggest that:
 - About 50 percent of the risk of developing fibromyalgia and related conditions, such as irritable bowel syndrome and headache, is genetic.
 - About 50 percent is environmental. (Kato 2009)
- Environmental factors most likely to trigger fibromyalgia include stressors involving acute pain that could last for a few weeks. (Buskila 2008)
- Fibromyalgia can be triggered by infections like Epstein-Barr virus, Lyme disease, Q fever and viral hepatitis. (Buskila 2008)
- Fibromyalgia can be triggered by trauma like motor vehicle collisions. (McLean 2011)
- Psychological stress has been shown to trigger fibromyalgia.
 - Fibromyalgia can be triggered by deployment to war. (Lewis 2012)

Health Burdens

- Fibromyalgia is a centralized pain state in which pain is experienced in different body regions at different times. (Williams 2009)

- Fibromyalgia may occur with other chronic pain conditions like osteoarthritis, rheumatoid arthritis and lupus. About 10 to 30 percent of patients with those diseases also meet the criteria for fibromyalgia. (Phillips 2013)
- Magnetic resonance imaging of brain response has shown that brain activation in fibromyalgia patients is increased, and they experience amplified pain (allodynia) for stimulus that people without fibromyalgia perceive as touch. (Gracely 2002)
- Patients with fibromyalgia may have imbalances, or altered activity of various neurotransmitters mediating pain transmission, which may affect mood, memory, fatigue and sleep. (Clauw 2014)
- Patients developing fibromyalgia commonly have lifelong histories of chronic pain throughout their body. Regional or widespread musculoskeletal pain occurs in about 30 percent of patients. (McBeth 2007)
- Fibromyalgia patients are likely to have a history of:
 - headaches
 - temporomandibular joint disorder
 - chronic fatigue
 - irritable bowel syndrome and other functional gastrointestinal disorders
 - interstitial cystitis/painful bladder syndrome
 - dysmenorrhea and/or endometriosis
 - other regional pain syndromes (especially back and neck pain) (Hudson 1994)

Twice as many women
are diagnosed with
FIBROMYALGIA
than men.

(Agarwal 2016)

- Living with fibromyalgia also has a significant emotional impact, with depression and anxiety being common comorbidities.

(Vincent 2015)

- Fibromyalgia symptoms result in significant functional impairment and a negative impact on patients' quality of life. Fibromyalgia patients report difficulties in:

- Establishing and maintaining physical and emotional relationships with others
- Adjusting personal expectations of what they can complete and goals they can achieve
- Dealing with mood disturbances, such as anxiety and depression
- Starting or continuing education or a career *(Arnold 2008)*

- Patients often have difficulty adjusting to living with fibromyalgia and sometimes feel a sense of loss of identity. *(Rodham 2010)*

- Patients also felt isolated from health care providers, whom they felt they had to convince they had a "real" condition to be taken seriously. *(Rodham 2010)*

- Patients have characterized living with fibromyalgia as having to manage two major burdens:

- pain, which can be ever-present and overwhelming
- invisibility, being doubted by others because the symptoms of fibromyalgia are subjective and not seen by others

(Juuso 2011)

- Many patients who have fibromyalgia (or like syndromes) may respond well to simple interventions like:

- stress reduction
- improved sleep patterns
- increased activity and exercise *(Clauw 2014)*

- The importance of behavioral therapies should be emphasized, as should be normalization of sleep patterns and institution of exercise therapy.

- Patients should understand that these treatments often will be more effective than pharmacological treatments.

(Fitzcharles 2013)

- Management should take the form of a graduated approach, with the aim of improving health-related quality of life.

- It should focus first on nonpharmacological modalities. But if there is lack of effect, there should be individualized treatment based on patient need. *(Macfarlane 2016)*

- Experts give a strong recommendation for the use of exercise, particularly given its effect on pain, physical function and well-being, and its availability, low cost and low-safety concerns.

(Macfarlane 2016)

- Aerobic exercise has been associated with improvements in pain and physical functioning. *(Busch 2008)*

- Resistance training can result in significant improvement in pain and function. *(Busch 2013)*

- Land and aquatic exercise appears equally effective in improving pain and function. *(Bidonde 2014)*

Economic Burdens

- On average, it often takes more than two years and about four consultations with different specialists to be diagnosed with this disease. *(Choy 2010)*

- Fibromyalgia represents a substantial economic burden for both the patient and the health care system:

- with increased costs for prescription medications
- lost productivity
- short-term disability *(Schaefer 2016)*

- Fibromyalgia symptoms directly affect a patient's ability to work, frequently resulting in missed workdays, reduction in hours and having to change jobs. *(Schaefer 2016)*



CONCLUSION

As the number of those affected by arthritis increases, the costs and other burdens to them and society at large will continue to grow.

Arthritis Foundation staff, volunteers and partners are working to address many issues preventing people with arthritis from accessing the treatment they need.

- To fight unaffordable out-of-pocket medical costs from inadequate insurance coverage, our tireless [Advocacy](#) champions are working hard to communicate with state and federal legislators to address our concerns and needs. Learn more about your [state's facts](#).
- There aren't enough specialists to serve the arthritis community; the traveling distance required to see trained providers and obtain needed services is unbelievable. We're addressing the challenges of the growing shortage of arthritis specialists, especially in underserved parts of the country, through our [Cultivating New Rheumatologists](#) program.

People with arthritis also want to learn more about research. That's why we've added the [Arthritis Trial Finder](#) – to help raise awareness and increase participation in arthritis-related clinical trials, accelerating the development of new drugs and treatments. Patients can run a personalized search and find active research studies in their area.

We continue to work toward research we believe will make the biggest impact going forward:

[Conquering Childhood Arthritis](#): Through work with our partnerships, we're laying the groundwork for revolutionizing treatments for JA, including personalized therapies that take away the guesswork. Working with our partners in the Childhood Arthritis and Rheumatology Research Alliance (CARRA), we co-hosted in August 2018 the externally-led [JIA Patient-Focused Drug Development](#) meeting. The patient findings from this meeting are incorporated into the JIA Voice of the Patient report, which has been submitted to the U.S. FDA for consideration in updating the guidelines and regulations surrounding JIA research.

[Advancing Osteoarthritis Treatment](#): Through our Clinical Trial Network and virtual OA Center of Excellence, we're speeding up the process of developing cutting-edge OA treatments and diagnostics that allow for earlier diagnosis.

[Collaborating With Patients](#): We're putting arthritis patients front and center of their treatment and care, so they have more control of how they feel and what they can do.

[Patient-Reported Outcomes \(PRO\)](#): As part of our [Live Yes! Arthritis Network](#), we've created short PRO surveys to help patients generate insights into their own well-being. Data collected will reveal individual and collective information about what works and what's needed in our communities. The surveys will collect data over time about physical health, social interaction, communication with health care providers and emotional health (including stress and depression).

We continue to advance our understanding of arthritis. By investing in additional scientific discoveries and supportive policies, we're confident we'll conquer this life-altering disease working together.

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APPENDIX 1

Types of Arthritis

The following is a list of arthritis and related conditions considered to be types of arthritis. For more information about each type of arthritis, visit arthritis.org.

- Adult-onset Still's Disease
- Myositis
- Ankylosing Spondylitis
- Osteoarthritis (OA)
- Back Pain
- Osteoporosis
- Behçet's Disease
- Pagets
- Bursitis
- Palindromic Rheumatism
- Calcium Pyrophosphate Deposition Disease (CPPD)
- Patellofemoral Pain Syndrome
- Carpal Tunnel Syndrome
- Pediatric Rheumatic Diseases
- Chondromalacia Patella
- Pediatric SLE
- Chronic Fatigue Syndrome
- Polymyalgia Rheumatica
- Complex Regional Pain Syndrome
- Pseudogout
- Cryopyrin-Associated Periodic Syndromes
- Psoriatic Arthritis (PsA)
- Degenerative Disc Disease
- Raynaud's Phenomenon
- Developmental-Dysplasia of Hip
- Reactive Arthritis
- Ehlers-Danlos
- Reflex Sympathetic Dystrophy
- Familial Mediterranean Fever
- Reiter's Syndrome
- Fibromyalgia
- Rheumatic Fever
- Fifth Disease
- Rheumatism
- Giant Cell Arteritis
- Rheumatoid Arthritis (RA)
- Gout
- Scleroderma
- Hemochromatosis
- Sjögren's Syndrome
- Infectious Arthritis
- Spinal Stenosis
- Inflammatory Arthritis
- Spondyloarthritis (SpA)
- Inflammatory Bowel Disease
- Systemic Juvenile Idiopathic Arthritis (sJIA)
- Juvenile Dermatomyositis (JD)
- Systemic Lupus Erythematosus (SLE)
- Juvenile Idiopathic Arthritis (JIA)
- Systemic Lupus Erythematosus (SLE) in Children & Teens
- Juvenile Scleroderma
- Systemic Sclerosis
- Kawasaki Disease
- Temporal Arteritis
- Lupus
- Tendinitis
- Lupus in Children & Teens
- Vasculitis
- Lyme Disease
- Wegener's Granulomatosis

APPENDIX 2

Arthritis Foundation-Funded Research

The story told through the statistics presented in *Arthritis by the Numbers* has gaps in knowledge that have been questioned by both patients and researchers. That doesn't stop us from continuing to ask questions and look for answers that are important to patients – and will eventually lead to a cure. We have included some of our patient reviewer stories in this edition. Another piece of the story comes from the donor-supported research our investigators have done to help find information to fill some of those gaps.

Our History

We have an impressive, research history. The Arthritis and Rheumatism Foundation, organized in 1948, became the Arthritis Foundation in 1964. Since our inception, the Foundation has supported research that strives to improve the lives of people with arthritis. As the timeline below shows, the time between discovery of a new drug or biologic and its approval for use may take decades.

1949 – First Grant

The Arthritis Foundation began our professional education program by granting funds to support the Seventh International Congress on Rheumatic Diseases, sponsored by the International League Against Rheumatism, held in New York City in 1949. One of the highlights of the Congress was a presentation of the effects of cortisone and adrenocorticotropin (ACTH) on patients with rheumatoid arthritis (RA). This was the first presentation on cortisone given at an international meeting of doctors and scientists, whose main interest was the study and treatment of rheumatic diseases.



1978 – Identification of Lyme disease

The guidance of an astute mother, Polly Murray, brought Lyme disease to the attention of the Arthritis Foundation and scientists when she recognized an abnormal number of kids with pediatric arthritis in her community, including her son. Without this patient involvement, the discoveries that led to better understanding and treatments for this disease may have taken longer.

In the mid-1970s, Lyme disease was recognized as a distinct disease, when a cluster of cases originally thought to be juvenile rheumatoid arthritis was identified in three towns in Connecticut. Two of the towns, Lyme and Old Lyme, gave the disease its name. The ensuing work, funded through the Arthritis Foundation, led to recognition of the infectious nature of the disease.



1982 – Arthritis Foundation-funded study on Methotrexate adds interest in using it for rheumatoid arthritis (RA) and other arthritis forms

Researchers first developed Methotrexate in the 1940s, as a treatment for several forms of cancer. In the 1950s and 60s, doctors began using an older form of this drug at lower doses to treat psoriasis, psoriatic arthritis and rheumatoid arthritis (RA). The older form of this drug was hard to manufacture, so a newer form was created. The newer form of this drug has been part of RA treatment for at least three decades.



APPENDIX 2

For some of this time, the rheumatology community was hostile to using an anti-cancer treatment for RA, and doctors were reluctant to submit their clinical study results due to fear of rejection from professional journals. However, in the early 1980s, researchers began to publish their results. That decade, the Arthritis Foundation was behind the earliest clinical trials, which set the stage for Methotrexate to become a mainstay of treatment for RA. An Arthritis Foundation-funded study, “Low dose Methotrexate in rheumatoid arthritis” (K. Steinsson, et al), published in the Journal of Rheumatology in late 1982, along with similar studies, provided data that led to the drug’s approval for treating arthritis.

In 1988, Methotrexate won FDA approval for treating RA, and it soon became the treatment of choice for people with this condition and other forms of inflammatory arthritis.

1983 – Identification of IL-1 fundamental to modern pediatric treatment

Only a handful of foundations can draw a direct connection between their work and FDA approved therapies.

Using his Arthritis Foundation research grant in the early 1980s, Dr. Bill Arend studied the role of interleukin (IL)-1 protein in rheumatoid arthritis (RA) – which ushered in the biologic era that led to the development of etanercept (Enbrel), anakinra (Kineret) and secukinumab (Cosentyx). These biologics owe their inventions to milestone discoveries funded by the Arthritis Foundation.

1998

• Enbrel (etanercept) approved TNF inhibitor

Enbrel is a biologic that treats autoimmune diseases by acting as a tumor necrosis factor (TNF) inhibitor. TNF-alpha is one of the main regulators of immune (inflammatory) responses in the body. Autoimmune diseases are caused by overactive immune responses. Enbrel inhibits the immune response caused by TNF-alpha. It is used to treat ankylosing spondylitis, juvenile idiopathic arthritis, psoriasis, psoriatic arthritis and rheumatoid arthritis.

• North American Rheumatoid Arthritis Consortium (NARAC) forms

This is a group of researchers across the U.S. who conduct research on the genetics of rheumatoid arthritis. Sponsored by the National Institutes of Health and the Arthritis Foundation, NARAC maintains a database and serum and DNA repository, which serves as a resource for the entire scientific community, allowing comprehensive analysis of genetic susceptibility to rheumatoid arthritis.



2000

• Kineret (anakinra) approved, based on IL-1 discoveries

Kineret is a biologic used to treat rheumatoid arthritis. It is a slightly modified version of interleukin (IL)-1, which inhibits immune responses.

• Childhood Arthritis and Rheumatology Research Alliance (CARRA) forms

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) is an organization of pediatric rheumatologists committed to advancing the health and quality of life of children living with rheumatic diseases. With financial support from the Arthritis Foundation, the American College of Rheumatology (ACR) and others, CARRA’s network of pediatric rheumatology research centers provides an accessible point of entry for patients and families across the United States and Canada to participate in research studies and trials of new therapies.



APPENDIX 2

2015 – Cosentyx (secukinumab) approved by FDA for ankylosing spondylitis and psoriatic arthritis

This biologic binds to the protein interleukin (IL)-17A and inhibits the immune response. Cosentyx was awarded the 2016 Prix Galien USA Award for Best Biotechnology Product. Prix Galien awards are the pharmaceutical industry's equivalent of a Nobel Prize, given for innovative medical research.

2017 – Launch of four (ongoing) scientific initiatives

The Arthritis Foundation is currently supporting scientific initiatives rolling out four specific initiatives, providing funding for:

- **Advancing Osteoarthritis Treatments**

Affecting more than 30 million Americans, osteoarthritis remains a huge issue and a serious condition. We are determined to find out more about this devastating disease and aid in the development of new and novel treatments.

- **Cultivating a New Generation of Rheumatologists**

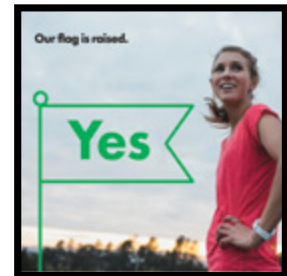
The growing shortage of rheumatologists – specialists devoted to diagnosis and therapy of rheumatic diseases – creates more barriers to care, and negatively impacts a patient's quality of life. Creating incentives, like our fellowship program, will increase the number of medical students choosing rheumatology.

- **Conquering Childhood Arthritis**

The Arthritis Foundation partners with the Childhood Arthritis and Rheumatology Research Alliance (CARRA), to not only fund research for disease treatment options, but also to activate large-scale patient engagement to compare the effectiveness of different treatments, both in the short- and long-term.

- **Collaborating With Patients for Better Health**

Real, patient-centered care is vital to ensuring better health outcomes. Our digital data exchange will enable patients to record symptoms, problems and challenges in real time – with results sent directly to their doctor. Communication between visits will enrich the care plan produced by both the doctor and the patient.



Recent Research Stories

The following is a list of blog posts telling the stories about some of our recent research projects.

Osteoarthritis Virtual Center of Excellence (OA COE)

These three initial OA COE demonstration studies are looking at anterior cruciate ligament (ACL) development in early posttraumatic OA (PTOA) patients. They are building on what they learned from earlier Arthritis Foundation-funded studies.

Dr. Xiaojuan Li – PTOA imaging (MRI) biomarkers

<http://blog.arthritis.org/news/arthritis-research-xiaojuan-li/>

Dr. Virginia Kraus – PTOA joint fluid and urine biomarkers

<http://blog.arthritis.org/news/tag/dr-virginia-byers-kraus/>

Dr. Christian Lattermann – early ACL treatment for PTOA

<http://blog.arthritis.org/news/arthritis-research-christian-lattermann>

APPENDIX 2

Delivering on Discovery Research Program

Prior to the development of the OA COE, the Arthritis Foundation funded many projects under the 2015-16 Delivering on Discovery and other earlier research programs. These projects are committed to accelerating the search for new solutions to arthritis. The projects listed below are arranged by arthritis indication.

OA

Dr. Hongsik Cho – A novel method of detecting and treating early PTOA

<http://blog.arthritis.org/news/arthritis-research-hongsik-cho/>

Dr. Bruce Cronstein – The role of adenosine receptors in OA

<http://blog.arthritis.org/news/arthritis-research-bruce-cronstein/>

Dr. Farshid Guilak

Blog 1 – Engineering new biologic therapies for arthritis

<http://blog.arthritis.org/news/arthritis-research-farshid-guilak/>

Blog 2: Arthritis Foundation investigator developing arthritis vaccine

<http://blog.arthritis.org/news/farshid-guilak-arthritis-vaccine/#more-837>

Dr. Virginia Kraus – OA and harmful bacteria in the gut and gums

<http://blog.arthritis.org/news/arthritis-research-virginia-kraus/>

Dr. Veronique Lefebvre – Reprogrammed stem cells that create cartilage

<http://blog.arthritis.org/news/arthritis-research-veronique-lefebvre/>

Dr. Richard Loeser – The role of diet and gut bacteria in OA

<http://blog.arthritis.org/news/arthritis-research-richard-loeser-jr/#more-1015>

Dr. James Martin – Engineering cartilage repair

<http://blog.arthritis.org/news/arthritis-research-james-martin/#more-904>

Dr. Tuhina Neogi – Bisphosphonate effects in knee OA

<http://blog.arthritis.org/news/arthritis-research-tuhina-neogi/>

Dr. Herb Sun – A novel formulation for OA prevention and treatment

<http://blog.arthritis.org/news/arthritis-research-herb-sun/>

Dr. Markus Wimmer – Augmented feedback using pressure detecting insoles for knee OA

<http://blog.arthritis.org/news/arthritis-research-marcus-wimmer/>

Rheumatoid Arthritis (RA)

Dr. Salah Ahmed – The effects of green tea on a protein found in RA joints

<http://blog.arthritis.org/news/arthritis-research-salah-ahmed/>

Dr. Christine Beeton – Scorpion venom as a potential source of RA treatment

<http://blog.arthritis.org/news/arthritis-research-christine-beeton/>

APPENDIX 2

Dr. Delesha Carpenter – How RA patients process conflicting treatment information

<http://blog.arthritis.org/news/delesha-carpenter-arthritis-research/>

Dr. Edward Doherty and Dr. Patricia Tilstam – Triggers for RA inflammation

<http://blog.arthritis.org/news/researchers-path-cure-spotlight-dr-edward-doherty/>

Dr. Jose Scher – The role of bacteria in the mouth, lungs and intestines in RA

<http://blog.arthritis.org/news/jose-scher-rheumatoid-arthritis-research/>

Dr. C. Michael Stein – How small RNA molecules in the blood may be markers for RA

<http://blog.arthritis.org/news/arthritis-research-c-michael-stein/>

Lupus (SLE)

Dr. Caroline Jefferies – How neutrophils (white blood cells) affect lupus lung disease

<http://blog.arthritis.org/news/arthritis-research-caroline-jefferies/>

Dr. Martin Kriegel – How protein produced by bacteria may be related to lupus

<http://blog.arthritis.org/news/arthritis-research-martin-kriegel/>

Juvenile Arthritis (JA)

Dr. James Jarvis – How genes expression is affected by the environment in JIA

<http://blog.arthritis.org/news/arthritis-cure-james-jarvis/#more-1000>

Dr. Jordan Orange – Targeting cellular stress to relieve symptoms of COPA syndrome

<http://blog.arthritis.org/news/arthritis-research-jordan-orange/>

Dr. Nora Singer – Using stem cell therapy to reset the immune system

<http://blog.arthritis.org/news/arthritis-research-nora-singer/>

Dr. Rae Yeung – Development of a tool to predict individual treatment responses

<http://blog.arthritis.org/news/arthritis-research-rae-yeung/>

CARRA/PARTNERS projects and researchers

We also fund a lot of research through various partnerships and collaborations. The list below is not all inclusive of our research outreach. However, it includes some of the bigger projects completed (or in progress) with the Childhood Arthritis and Rheumatology Research Alliance (CARRA) and Patients, Advocates and Rheumatology Teams Network for Research and Service (PARTNERS).

2018 CARRA large and small grants

<http://blog.arthritis.org/news/carra-arthritis-foundation-grant-awardees/>

Educational videos about patient partner/participant opportunities in research

<http://blog.arthritis.org/juvenile-arthritis/patients-research-opportunities/#more-290>

APPENDIX 2

A new way to compare how different treatments work for pediatric patients

<http://blog.arthritis.org/juvenile-arthritis/treatments-pediatric-rheumatic-diseases/>

Funding research coordinators for juvenile research across the country

<http://blog.arthritis.org/juvenile-arthritis/funding-national-research-coordinators>

2018 Spring Small Childhood Research Grants

<http://blog.arthritis.org/news/spring-2018-childhood-research-grants/>

PARTNERS Pediatric Learning Health System: JIA project focus on improving outcomes

<http://blog.arthritis.org/news/partners-pediatric-learning-health-system/>

Collaborating With Patients for Better Health: Rheumatology Learning Health System (RLHS)

Real, patient-centered care is vital to ensuring better health outcomes. The RLHS is key to this scientific initiative goal: Our digital data exchange will enable patients to record symptoms, problems and challenges in real time – with results sent directly to their doctor. Communication between visits will enrich the care plan produced by both the doctor and the patient.

2018 Proof of Concept Pilot Study

<http://blog.arthritis.org/news/rheumatology-learning-health-system-pilot-network>

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