

LUPUS IN MEN

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Relevant Disclosures

- I have nothing to disclose
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Outline

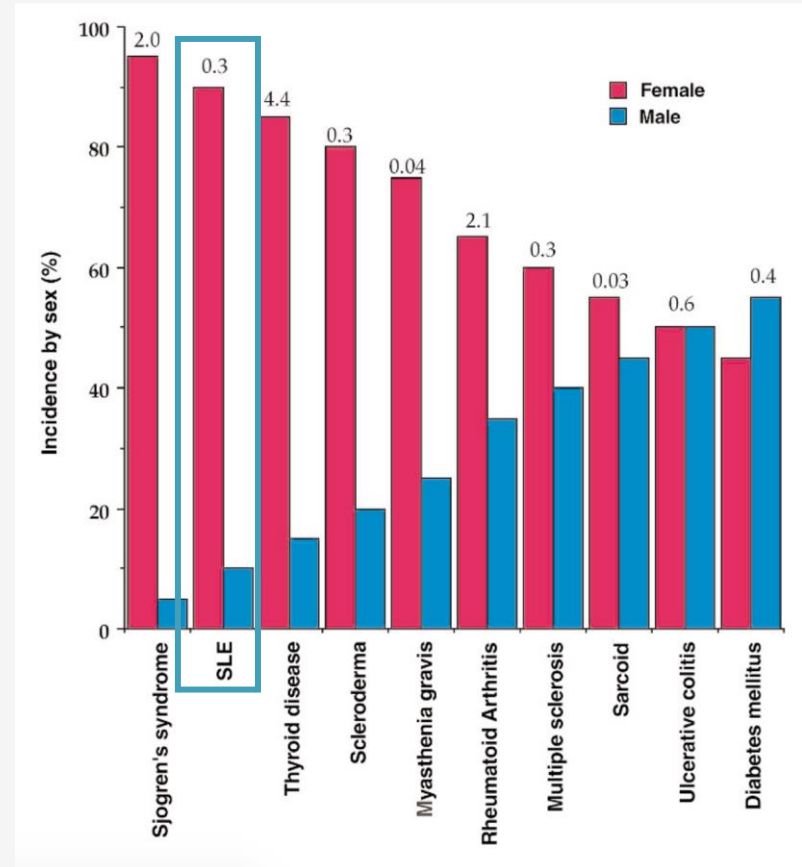
- Do men get lupus?
 - Does it look the same as lupus in women?
 - Does lupus or treatments affect male fertility or testosterone levels?
 - Do men and women get equal treatment? If not, why not?
 - Are there resources for men with lupus?
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Do Men Get Lupus?


- **Definitely!**
 - **1/10 of lupus patients in the general population are men (range 4-22% depending on study)**
 - **Family history of men with lupus? Higher likelihood**
 - **Pre-puberty or post-menopause? Still more women, but less drastic of a split**
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Why the imbalance?

- In general, autoimmune disease is seen more often in women anyway, but this is skewed even more in lupus
- Theories as to why:
 - Testosterone protective?
 - XX vs. XY chromosomes?
 - Bias: are we underdiagnosing male lupus?



Caveat

- Most of my statements are based on a limited high quality evidence
 - Rarer in men = less patients for study
 - More study and information could change current opinions
 - The CDC is currently funding 5 locations gathering data about lupus patients in the US: California, Georgia, Michigan, the Mayo Clinic, and University of Utah
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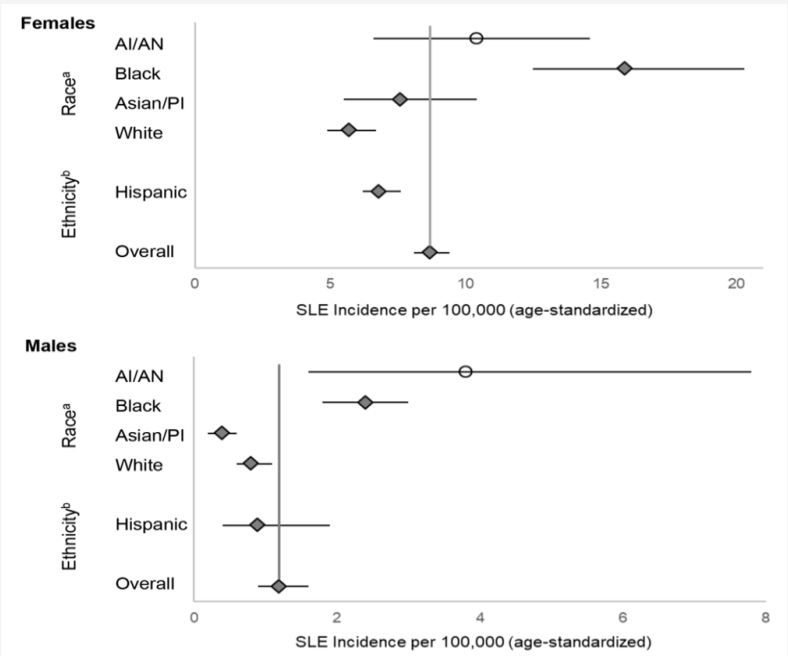
Ethnicity of Men with Lupus

<----- Less risk || More risk ----->

Black, Native American men had higher risk than white or Asian men

Incidence rates of systemic lupus erythematosus in the USA: estimates from a meta-analysis of the Centers for Disease Control and Prevention national lupus registries

Peter M Izmirly ¹, Elizabeth D Ferucci ², Emily C Somers ³, Lu Wang, ⁴
S Sam Lim ⁵, Cristina Drenkard ⁵, Maria Dall'Era, ⁶ W Joseph McCune, ⁷
Caroline Gordon, ⁸ Charles Helmick, ⁹ Hilary Parton ¹⁰



Does it look different in men than women?

There are split opinions on this topic, but several things are known about:

Age at
Diagnosis

Severity of
disease

Particular
features of
disease

Age at diagnosis

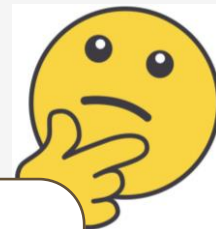
Women

15 – 44 Years old

Men

30 - 50 Years old

- **TAKE HOME POINT:** If you're a man with lupus, you have a higher chance of being diagnosed later



Food for thought:
Does the disease start later or just get diagnosed later? Or both?

Severity of Disease

Comparative Study

> [Arthritis Rheum. 2007 Feb;56\(2\):622-30. doi: 10.1002/art.22375.](#)

Accelerated damage accrual among men with systemic lupus erythematosus: XLIV. Results from a multiethnic US cohort


[Rosa M Andrade](#) ¹, [Graciela S Alarcón](#), [Mónica Fernández](#), [Mandar Apte](#), [Luis M Vilá](#), [John D Reveille](#),
[LUMINA Study Group](#)

LUpus in MInorities, NAture versus nurture cohort, a multiethnic cohort consisting of Hispanic, African American, and Caucasian patients


- Looked at **63 men** with lupus (and many more women) and compared markers of damage from lupus (using criteria called the SLICC/ACR criteria)
- All patients had lupus for less than 5 years (**Early disease**)

Men were significantly more likely to have damage from lupus at baseline, and also more likely to get damage from lupus as their disease went on

Severity, Continued

- Some, but not all, studies suggest men have a higher risk of dying from lupus
 - Some, but not all, studies suggest men have more resistance to treatment than women
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Take Home Points

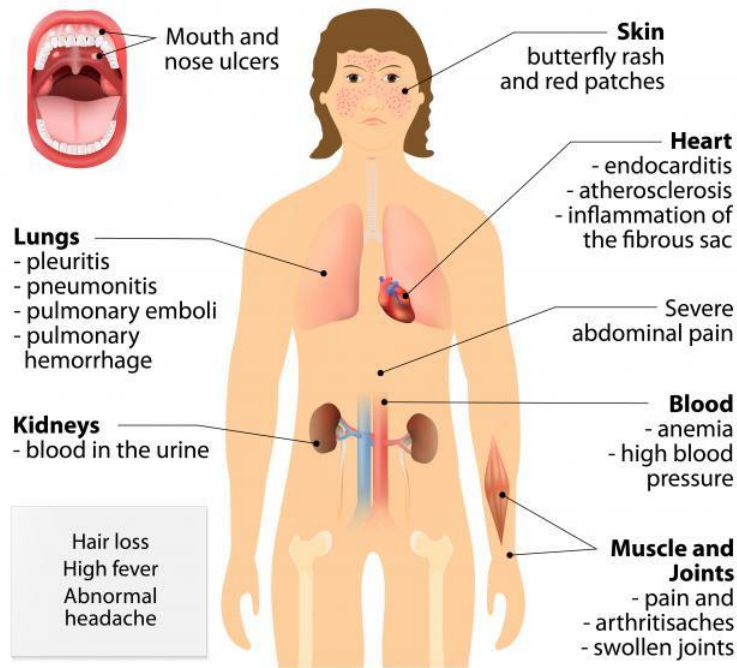
- Some think that these findings mean lupus is **MORE AGGRESSIVE** in men despite being **MORE COMMON** in women
 - There is **DEBATE** around this topic, because there could be many other good reasons for these observations (example: men could be bad at taking their medicines), and they are not **CONSISTENTLY** demonstrated by large studies
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Disease Features

Note: Any individual man or woman with lupus can have any individual lupus feature

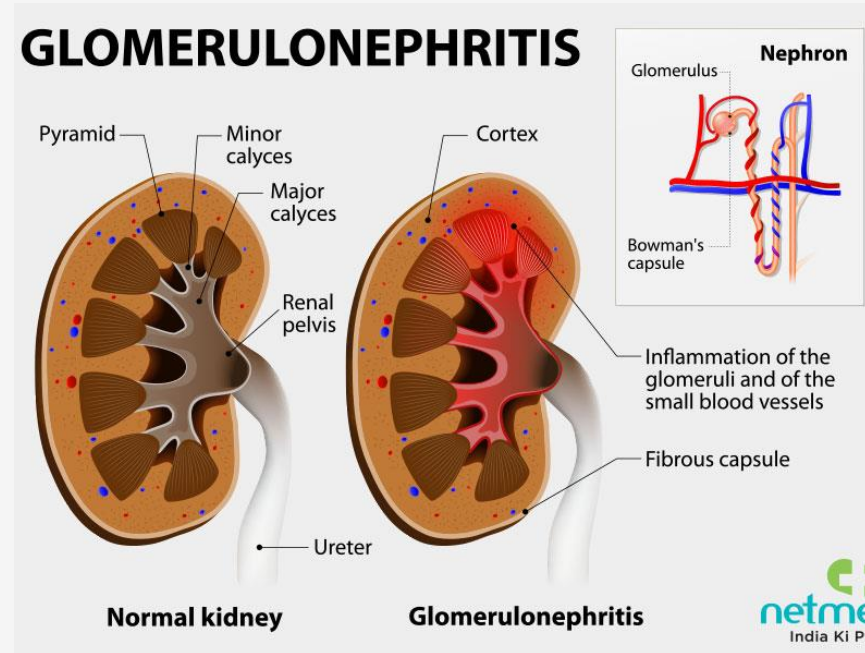
The following slides are talk about the observed *chances* of men vs. women getting the particular feature

Systemic lupus erythematosus



1. *Kidney Lupus (Lupus Nephritis)*

- Men seem to get more kidney lupus, and this is the feature that probably has the best evidence behind this claim
- At least 12 papers that I reviewed comparing men to women did note increased chance of this
- Higher risk of kidney failure and need for dialysis in men
- Unclear reasons



2. Other Features

- Several large trials but many done in EUROPE with a more CAUCASIAN POPULATION

Increased Risk for MEN Include:	
Increased Risk of Blood Lupus	Low blood counts
	Swollen lymph nodes
	Blood clotting
	Antiphospholipid syndrome
Increased risk of neuropsychiatric lupus	"Brain lupus"

Features more likely in women

- Again debatable

Fibromyalgia

Sjogren's
syndrome
(dryness
syndrome)

Raynaud's

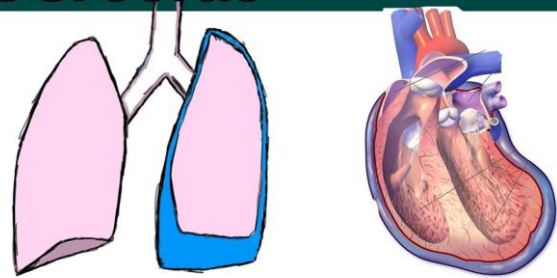
Acute cutaneous
lupus- the
butterfly rash

Seen reasonably equally in both

- Arthritis
 - Joint pain and sometimes swelling
 - Serositis
 - Fluid gathering around the heart or lungs
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Serositis



Takeaways

- Men **appear to be** at higher risk for more internal organ involvement, and women tend to have a higher chance of the exterior manifestations of lupus, at least according to existing studies in several populations
 - Many grains of salt
 - Maybe mild lupus symptoms are never diagnosed as lupus in men, underestimating how many men have lupus and how many men have mild vs. severe internal lupus
 - Maybe men have other behaviors or tendencies to explain these differences; higher rates of smoking or high blood pressure or medication nonadherence or other factors
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Does Lupus Affect Fertility and Testosterone?

- Mostly, we don't think so
- We don't usually see a decrease in testosterone levels of men with lupus
- Most men with lupus are fertile and have a normal ability to father children
- At least one study suggested a portion of men with lupus had decreased testicular volume or sperm function, but some of these men were on culprit medications



Lupus Treatments and Fertility

- Most lupus medicines don't affect fertility at all
 - The one exception is Cyclophosphamide
 - May affect sperm counts in the short (and even long) term
 - Sometimes, if fatherhood is desired, a medicine called lupron is given prior to cyclophosphamide
 - Use of heavy doses of steroids may temporarily decrease the amount of sex hormones made, though this does not necessarily come with long term harm
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What are the barriers to better care?

Men	Doctor
Not knowing lupus in men exists	Not suspecting lupus in men
Stigma of having a “woman’s disease”	Not addressing psychosocial factors of men with lupus
Our own ego and need for toughness	
Poorly aligned goals of treatment, poor education about the disease and the prognosis	

Other Factors to Consider

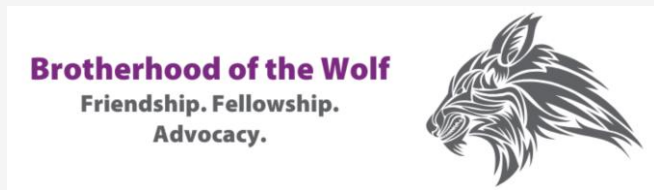
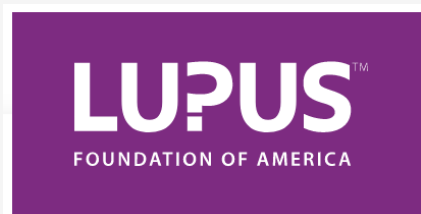
- Finances: In some families, men are still the breadwinner or at least expected to work
 - Flares may cause you to miss work
 - Doctors visits and lupus treatments are expensive and may cause you to miss more work
- Isolation: Less social support
 - Part of this is less men with the disease to be able to lean on
 - Part may be the tendency of some men to isolate rather than lean on others



My Two Cents

- Lupus is chronic in most people, and may go up and down in terms of activity. You may even feel normal sometimes
 - Know that your disease may do this
 - Know that most people require some form of treatment, and that unfortunately that usually requires some amount of medicine
 - Know that many people can live full, relatively normal lives if they're treated properly
 - **Lean on others. Don't carry the weight all by yourself. Don't try to understand everything at once. Listen to your body. Find reliable resources to educate yourself. Get a healthcare team that you trust.**
 - **For men: You are absolutely no less of a man for having lupus. Use your strength and toughness to combat it right**
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Resources for Men



Inspire > LupusConnect

LupusConnect

Lupus Support and Discussion Community

Resource Center | Take Action | Local Support | Contact a Health Educator | Donate

 Join Inspire

 Create a Post

- [Lupus.org](https://www.lupus.org) – Does lupus occur in men?
- [Brotherhood of the Wolf](#) is an in person support group with a chapter in Georgia and some other chapters throughout the US
- [Lupusconnect](#) is an online forum if there is no in person support group

Summary

- Men get lupus, though it is true that 90% of lupus patients are women
 - Men often get diagnosed later, either because the disease starts later or they are misdiagnosed for longer
 - Men often have more severe lupus with more kidney problems, either because they don't get treated quickly or because of factors we don't know about
 - Lupus has questionable effects on sperm and testosterone. Mostly, we think there that a man with lupus should be able to father children
 - The main lupus treatment that may cause low sperm counts is cyclophosphamide.
 - Men are less likely to get proper care and need it as much or more than women
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THANK YOU FOR LISTENING!

Let me introduce our next speaker...



Key References

- Ramírez Sepúlveda, J.I., Bolin, K., Mofors, J. *et al.* Sex differences in clinical presentation of systemic lupus erythematosus. *Biol Sex Differ* **10**, 60 (2019). <https://doi.org/10.1186/s13293-019-0274-2>
 - Lu LJ, Wallace DJ, Ishimori ML, Scofield RH, Weisman MH. Review: Male systemic lupus erythematosus: a review of sex disparities in this disease. *Lupus*. 2010 Feb;19(2):119-29. doi: 10.1177/0961203309350755. Epub 2009 Nov 27. PMID: 19946032; PMCID: PMC7304291.
 - do Socorro Teixeira Moreira Almeida M, da Costa Arcoverde J, Barros Jacobino MN, Coimbra Neto AR. Male systemic lupus erythematosus, an overlooked diagnosis. *Clin Pract*. 2011 Nov 8;1(4):e103. doi: 10.4081/cp.2011.e103. PMID: 24765344; PMCID: PMC3981404.
 - <https://www.lupus.org/resources/does-lupus-occur-in-men>
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