

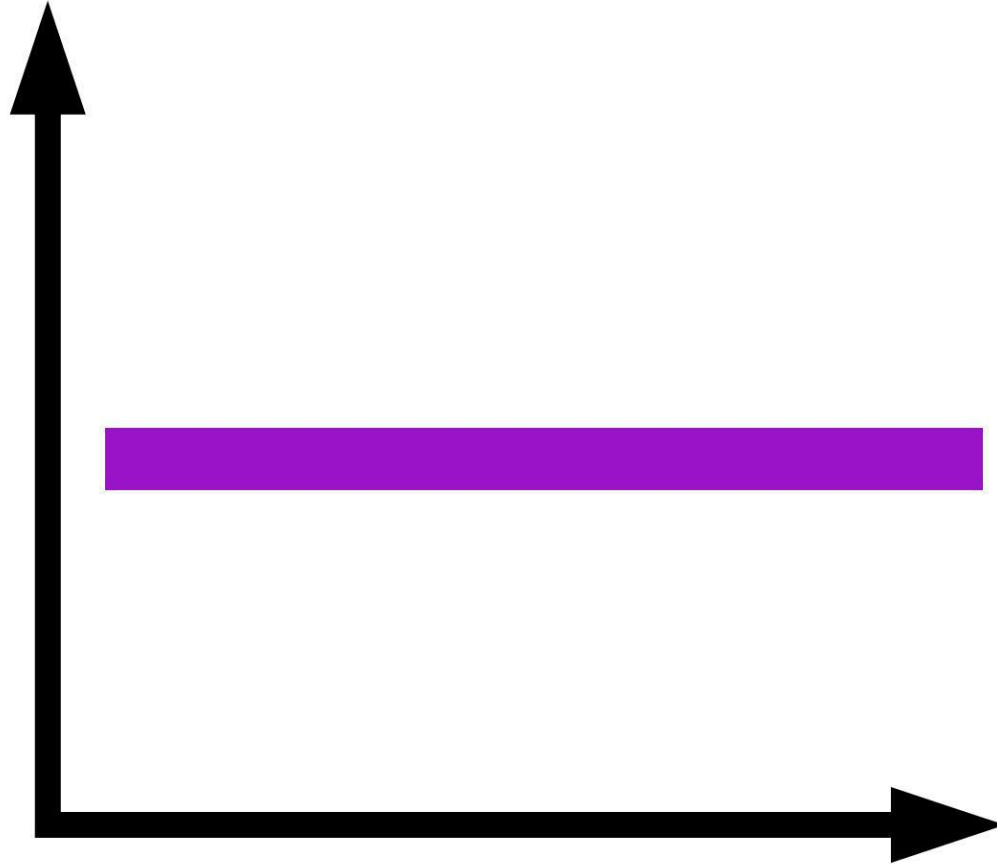
Lupus 101: Understanding Lupus

LFA - Georgia

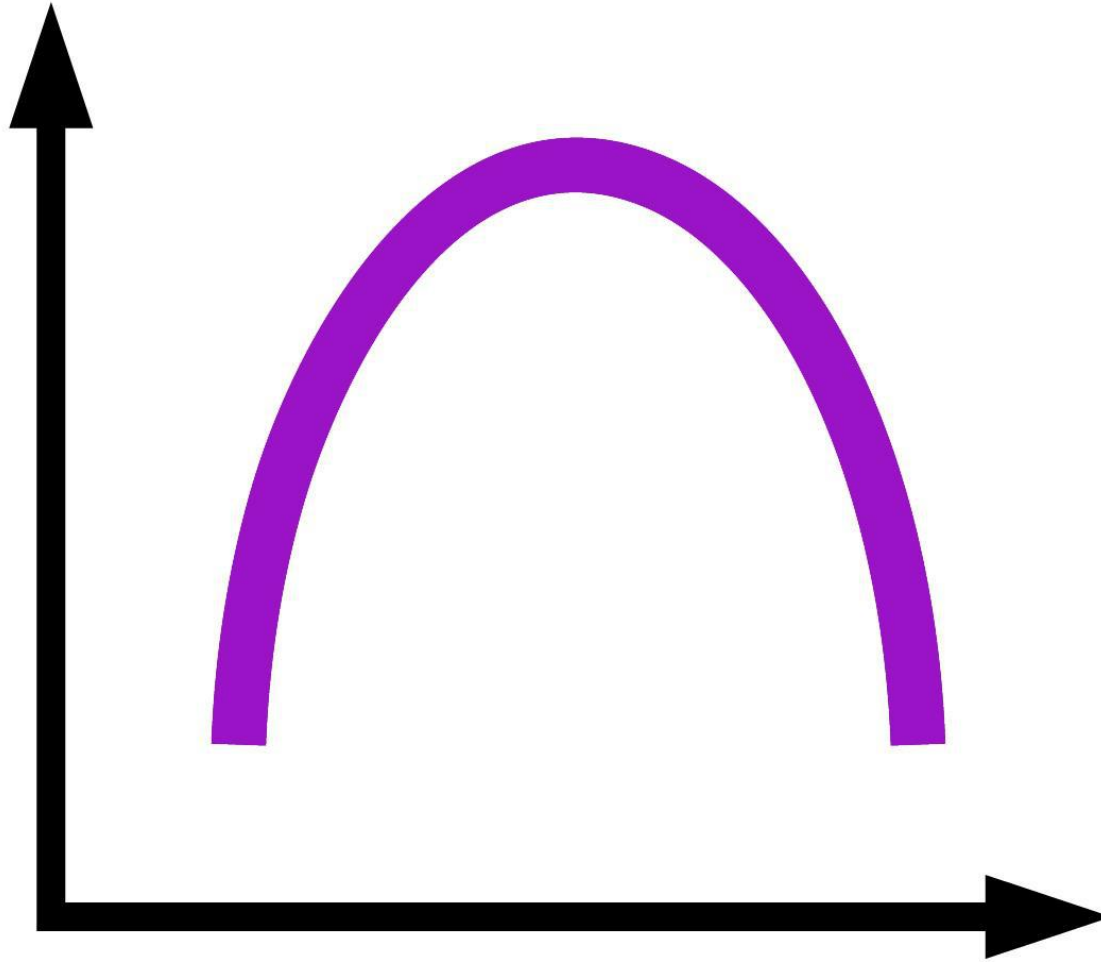
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Arthritis and Rheumatology of GA

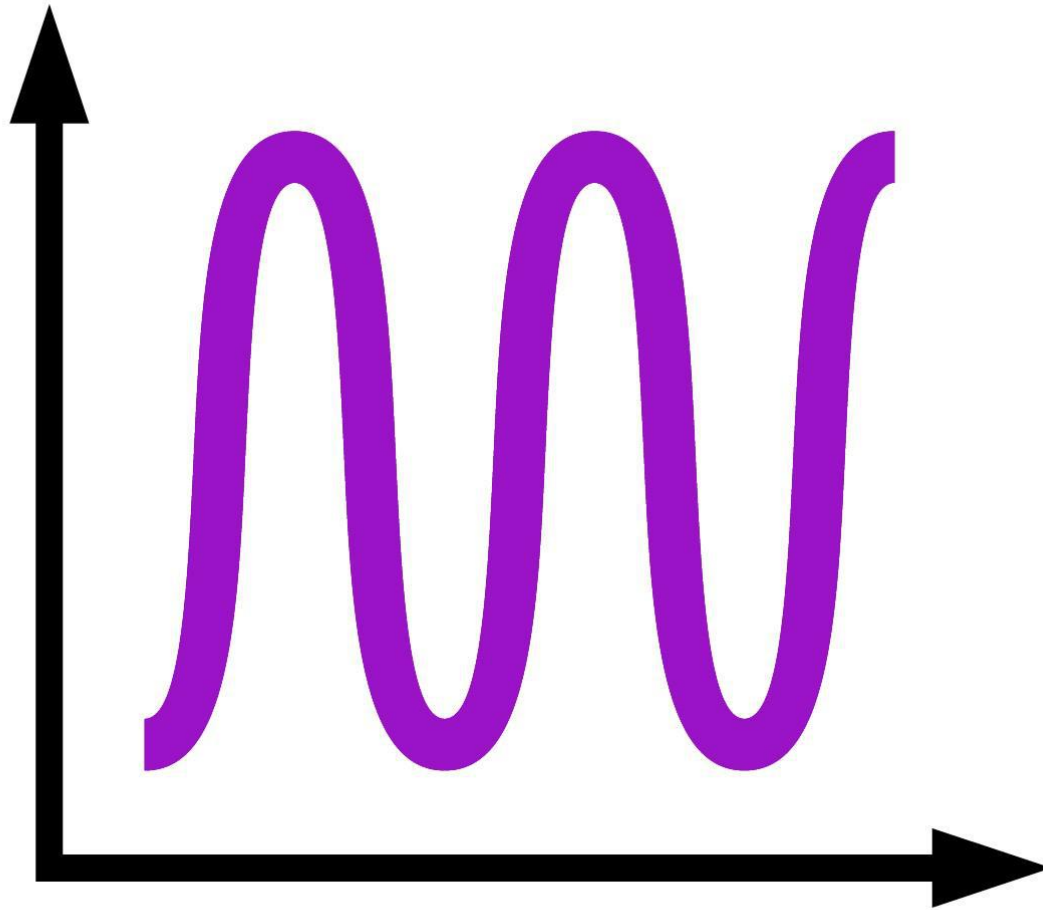
LUPUS – A REALITY CHECK



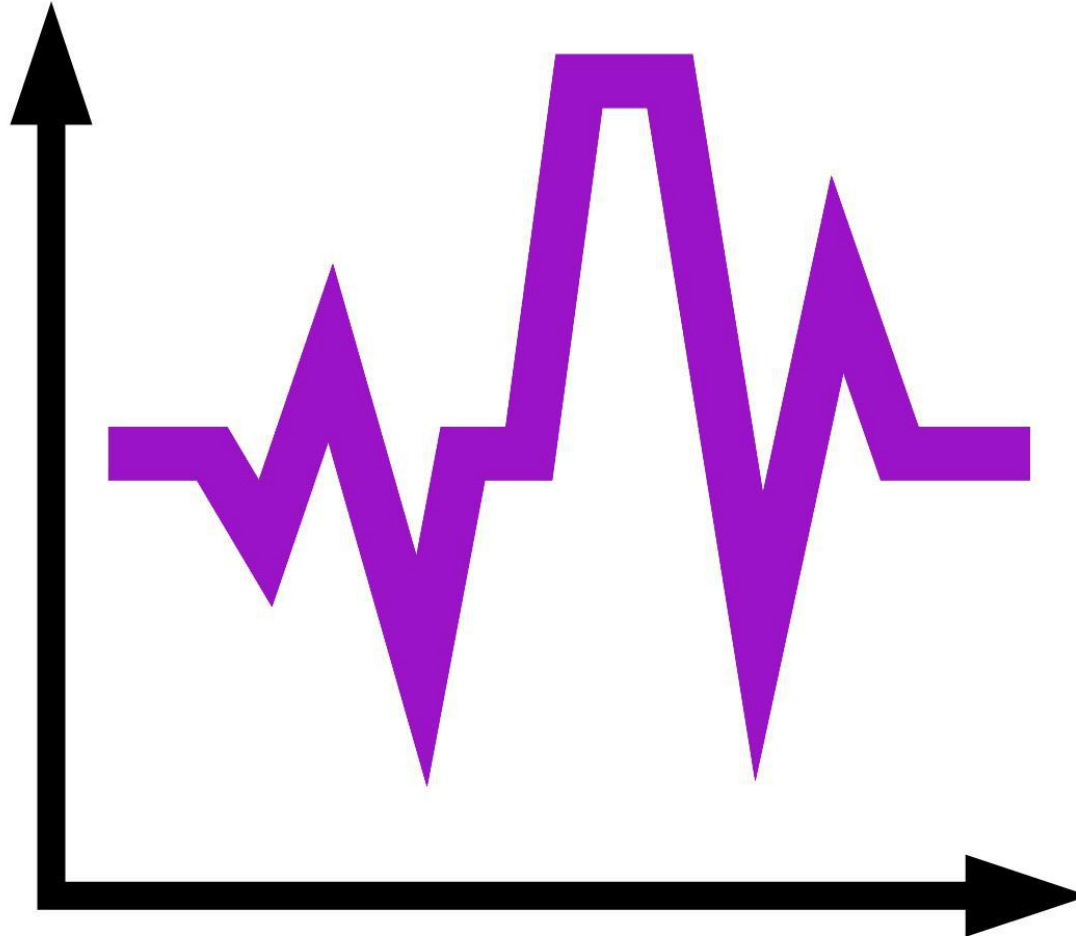
LUPUS – A REALITY CHECK



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SLE

- 1.5 million Americans: some form of lupus
 - 90%: women
 - 80%: 15-45 years old
 - 2-3 x more common among people of color (African American, Hispanic/Latino, Asians, Native Americans)
- Cause unknown...need
 - Vulnerable host- ? hormones
 - Environment- stress, UV light, infection (viral)
 - Genetics (10-20% if parent/sibling SLE)

What is lupus?

SLE (Lupus)

- Autoimmune disease
 - Body's immune system attacks self
 - antibodies (proteins) that attack body cells and tissues
 - cause inflammation, pain, damage
- Types of lupus
 - **Systemic (70%)**
 - any part of the body (joints, skin, kidney, brain)
 - Discoid (10%)
 - skin only
 - Drug-induced
 - certain medications
 - Neonatal
 - affects some newborns –
 - mom + anti-SS-A and/or SSB

Malar Rash



SLE Symptoms

(abbreviated list)

- Aching joints (*arthralgia*) or Swollen joints (*arthritis*)
- Hair loss (alopecia, patchy)
- Mouth or nose ulcers
- Chest pain with deep breath (pleuritis)
- Kidney involvement
- Skin rash
- Butterfly rash
- Raynaud's phenomenon
- Seizures

- Blood disorder

- Fever (>100°F)
- Fatigue: prolonged/extreme

Diagnosis: 'ACR Classification Criteria'

1. Malar Rash
2. Discoid Rash
3. Photosensitivity
4. Oral ulcers: painful OR painless
5. Arthritis (2 or more joints)
6. Serositis: lung (pleuritis), heart lining (pericarditis)
7. Kidney Disorder (protein, blood in urine)
8. Brain disorder (seizures, other psychological issues)

Diagnosis: 'ACR Classification Criteria' (cont)

9. Low WBC, RBC, or platelets (*leukopenia*, *anemia*, *thrombocytopenia*)
10. Abnormal blood clotting problems
11. ANA: antinuclear antibody blood test +
12. other (+) antibody tests

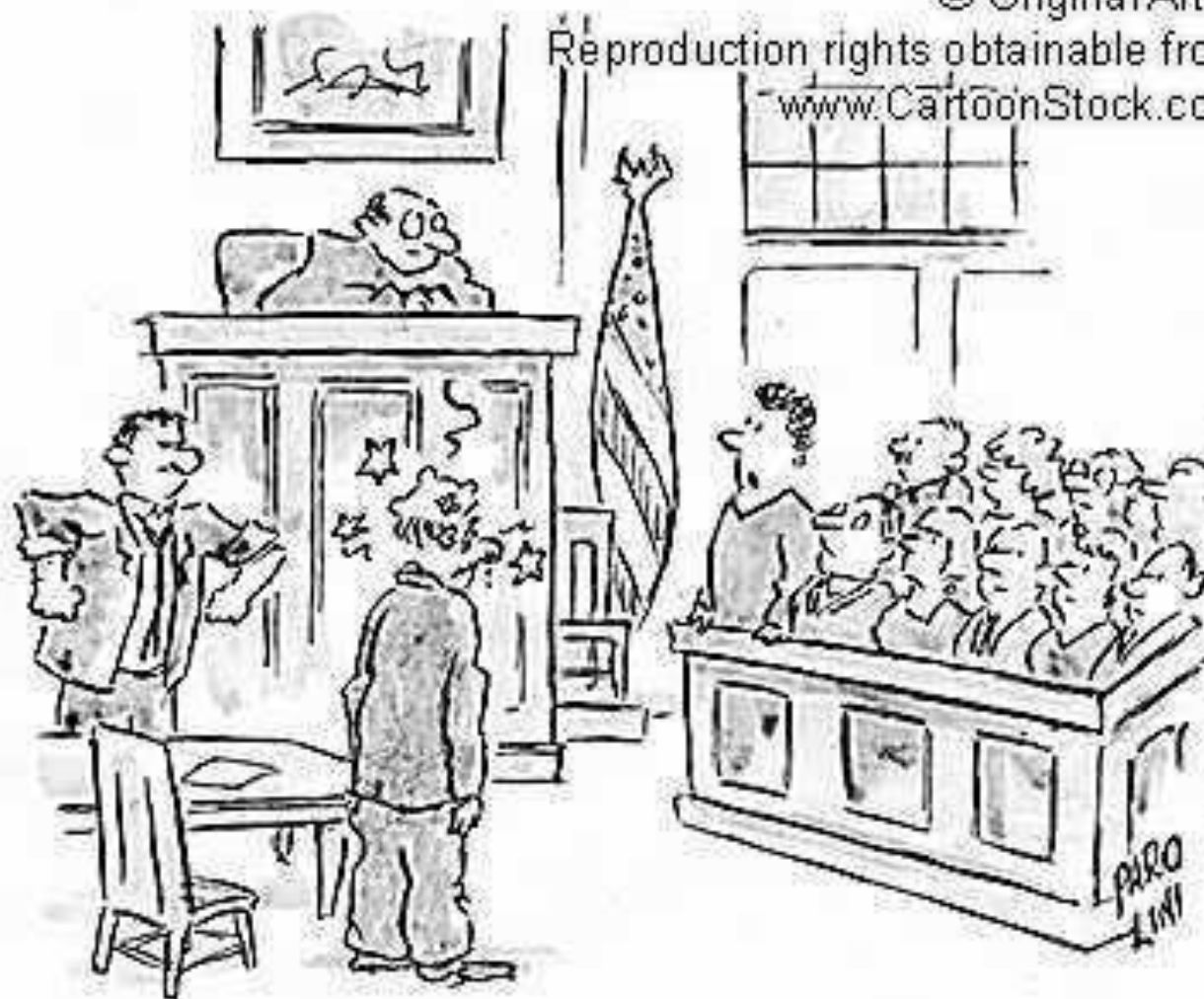
Diagnosis is NOT based
on a laboratory test

Laboratory tests support the clinical
findings but

NO LAB TEST NEGATIVE PATIENTS

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search ID: epa0427

"Your Honor, we feel that the prosecutor has done a 'bang up job', and the defendant has suffered enough."

Things that can activate lupus

- UV Light
 - Use sunscreen
 - At least SPF 60
 - Need UVA/UVB protection
 - Reapply 2-3 times if exposed to water/ very sunny
 - Wear sun protective clothing
 - Wide-brimmed hat
- Avoid substances that can cause flares
 - Echinacea- herbal for colds
 - Co Q 10
 - Melatonin- herbal for sleep
 - Alfalfa sprouts

Things that can activate lupus

- Be wary of estrogen hormones
 - Pregnancy, BCP and HRT
- Stress
 - minimize
- Medications
 - sulfa containing medications
 - Stopping certain medication abruptly especially steroids (prednisone)

Lupus Activity

- Examples
 - Inflamed joints
 - Myositis
 - Nephritis
 - Rashes (inflamed skin)
 - Fever
 - Pleuritis
 - Pericarditis
 - Low blood counts

Treatment

You and your Rheumatologist are partners against lupus!

- Ask questions! Communicate!
- Help your rheumatologist help you:
diary, pictures

Medications

NSAIDs and Tylenol

- NSAIDS (naproxen/Aleve, ibuprofen/Motrin, meloxicam/Mobic, diclofenac, celecoxib/Celebrex ...)
 - Help mainly with mild inflammation (except Tylenol) that can lead to achiness, joint symptoms
 - Take with food (protect your stomach)
 - Not if kidney problems or if on coumadin (ask your MD)

Corticosteroids

- The ultimate anti-inflammatory
 - oral: prednisone and medrol
 - IV or IM forms
 - Different from anabolic steroid use in athletes
- May be necessary to control active lupus; in cases of mild lupus, may be able to be avoided
- If body is stressed (other illness, operation- may need ‘stress’ doses- consider Medi-alert bracelet)
- Treatment with steroids should always be kept at the lowest possible effective dose
- NEVER stop suddenly! Decrease according to your rheumatologist’s direction
- Exercise and watch your diet BEFORE weight gain

Side effects

- Short term use;
mood changes, increased appetite,
acne, fragile skin (easy bruisability),
infection risk (with higher dose)
diabetes, increased bad cholesterol,
- Long term side effects:
osteoporosis (prophylaxis if > 10-12 weeks),
Cushingoid features, cataracts,
dependence (adrenal gland insufficiency)

Antimalarials

- hydroxychloroquine (Plaquenil), chloroquine (Aralen), quinacrine (Atabrine)
- Can be effective in controlling fatigue, joint symptoms and skin (also in discoid lupus) due to lupus
- ***Decreases
 - Need for prednisone
 - Risk of severe organ damage
 - Death
- May reduce numbers of future activity flares

Antimalarials (cont)

- Side effects (10%) may include; rash, skin pigment changes, dry skin, headache, dizziness, GI
- Has “good” side effects: improves cholesterol and circulation
- Baseline and every 6-12 month retinal exams/ visual field
- Retinal toxicity EXTREMELY RARE with Plaquenil; 10% with chloroquine
- Smoking decreases effectiveness

Immunomodulatory Drugs 'Steroid-Sparing'

- Imuran (azathioprine)
- Methotrexate
- Cytoxan (cyclophosphamide)
- Cellcept (mycophenolate mofetil)
- ? Rituxan (rituximab) ?

Immunomodulatory Drugs

- In SLE may help to
 - Prolong life
 - Preserve kidney function
 - Reduce disease symptoms
 - Reduce damage to vital organs, such as the kidneys and lungs
 - Sometimes induce disease remission
 - Reduce the need for steroids

Immunomodulatory Drugs

- Side Effects
 - Infection
 - Always call/see your PCP (or ED) : fever/chills, cough, sore throat, painful/frequent urination
 - Sometimes difficult to distinguish between infection and SLE flare
 - Lowered blood counts: CBC every 4-8 weeks
 - Liver problems : LFTs every 4-12 weeks

RECENT Rx – What's new??

BENLYSTA (belimumab)

- monoclonal antibody that inhibits the biological activity of a naturally occurring protein called B-lymphocyte stimulator or BLyS.
- BLyS is required for the creation of plasma B cells that produce the AUTO-antibodies
- Studies - are they for me??

Osteoporosis

- Caused by inflammation, steroids, inactivity
- Calcium
 - 1200-1500 mg/day
 - 300 mg= 8 oz yogurt or skim milk, 2 cups cottage cheese
 - supplements (need w/Vit D)
- Vitamin D
 - 800 – 1000 IU
 - Milk, Calcium supplements, multivitamin
- Weight Bearing Exercise 30 min 5 d/week
- Ask MD about bisphosphonates if on prednisone
- Yearly DEXA scan

Depression

- It is OK (and important to your overall health) to **ask for help**!!!
 - Psychologist: coping skills
 - Antidepressants
 - Support Groups
 - Psychiatrist
 - involve family/significant others

Cardiovascular Disease

- Heart attack, stroke, blood clot: 1/4 to 1/3 of all lupus deaths
- Heart Disease: leading cause of death in lupus
 - Lupus patients get at younger age
- Know and control risk factors:
 - Cholesterol
 - WEIGHT and EXERCISE
 - Blood Pressure
 - Diabetes

Contraception

- Oral contraceptives
 - SELENA OCP trial*: women with stable active or inactive lupus assigned to 1 year of OCP or placebo. No increase in flares with OCP
 - NOT in unstable lupus, increased tendency to clot [antiphospholipid antibodies, prior clot, nephrotic syndrome, cardiovascular/vascular disease]

*Petri M et al. (2005). Combined oral contraceptives in women with Systemic lupus erythematosus. *N Engl J Med*; 353: 2550-8.

Hormone Replacement Therapy (HRT)

- Hormone replacement trial in lupus
 - Randomized 351 menopausal lupus pts to 0.625 mg of estrogen daily plus 5 mg medroxyprogesterone for 12 days/month vs placebo for 12 months
 - No difference in severe flare rate but mild/moderate flares significantly increased in the HRT group

Bunyon JP et al (2005). The effect of combined estrogen and progesterone hormone replacement therapy on disease activity in systemic lupus erythematosus: a randomized trial. *Ann Intern Medicine*; 142: 953-62.

Before Pregnancy

- PLAN !!!!
- Disease activity should be well-controlled
- Under direction of rheumatologist change to non-teratogenic medications well BEFORE conception
- Labs having implications:
 - Antiphospholipid / anticardiolipin antibodies
 - Anti-Ro (SS-A) &/or Anti La (SS-B)

Impact of Pregnancy on Lupus Activity

- Pregnancy probably increases lupus activity
 - approximately 50% of women will have measurable lupus activity during pregnancy
 - most of the disease activity will be mild to moderate
 - 15% to 30% of women will have highly active SLE in pregnancy
- Most common types of lupus activity in pregnancy:
 - Cutaneous disease, arthritis, hematologic (anemia)
- Risk factors for increased lupus activity
 - active lupus within the 6 months before conception
 - multiple flares in the year before conception
 - discontinuation of hydroxychloroquine

Clowse M (2007). Lupus activity in pregnancy.
Rheum Dis Clin N Amer; 33: 237-252.

Vaccinations

- Try to get before starting significant immunomodulatory drugs (Imuran, MTX, Cytosan, Benlysta)
- Pneumovax
 - Prevents pneumonia from pneumococcus bacteria
 - Pneumonia- most common cause of death from infection in lupus
 - Every 5 years
- Influenza (flu)
 - Kills 20,000-30,000 each year
 - Every fall
- H1N1
 - Most lupus patients at higher risk for complications. Stay tuned for guidance.
- Tetanus/diphtheria/pertusis
 - Booster every 10 years
- **AVOID live vaccinations if on immunosuppressant meds**
 - MMR, Shingles, nasal influenza, OPV, BCG, Typhoid, Yellow Fever, Vaccinia, Zostavax

Take Control

- Keep a careful record of your history
- Know your disease and it's symptoms
- KNOW and keep LIST of current medications (keep it with you)
- KNOW and keep LIST of past medications, any problems/why stopped
- Keep your MD appointments/ ask ?s /communicate
- Help keep other MDs 'in the loop'

Utilize the LFA chapter

- support groups
- other seminars
- Lupus Now Magazine
- Webinars
- advocacy
- fund raising

Someone you know has lupus !