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To live with lupus, we need to know about lupus.

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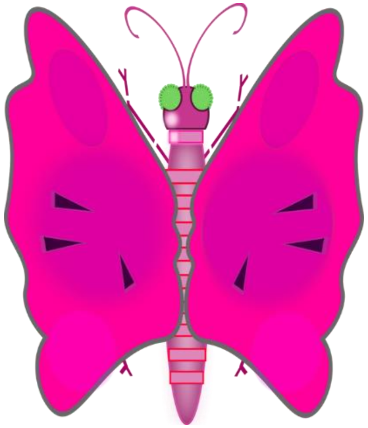
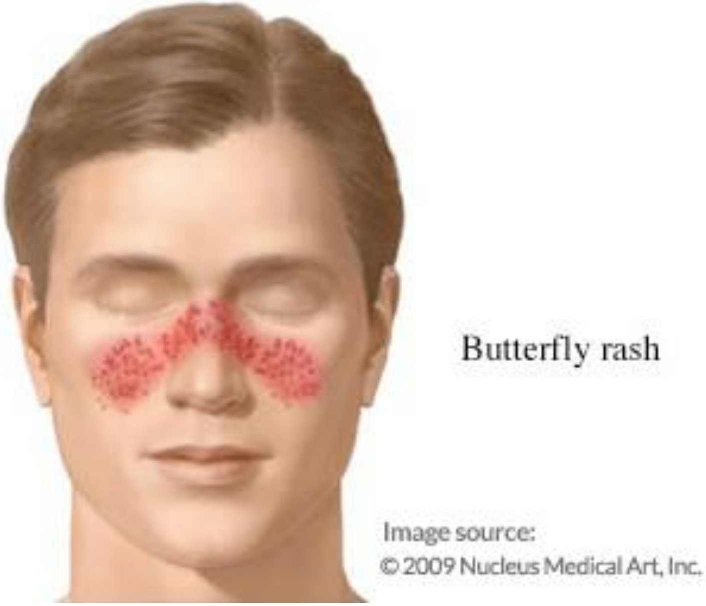
Where did the word “lupus” come from?



- The word ‘lupus’ is derived from the Latin word for “wolf”.
- Named in the 13th century by the physician “Rogerius”.
- He described the rash as erosive facial lesions as a consequence of a wolf's bite.
- The facial rash is also called “Butterfly rash”

because it resembles a butterfly shape.



Butterfly rash

Image source:
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What is lupus?

- Lupus is an autoimmune disease.
- It causes chronic inflammation in the body.
- It can affect any organ of the body such as the kidneys, gastrointestinal tract, lungs, heart, and joints.

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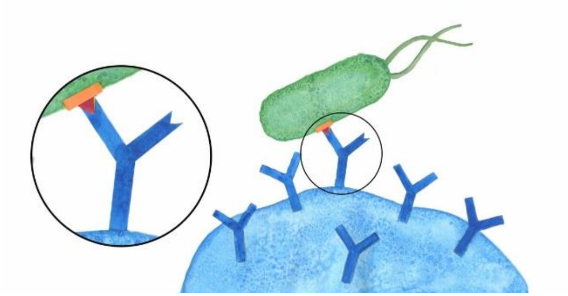
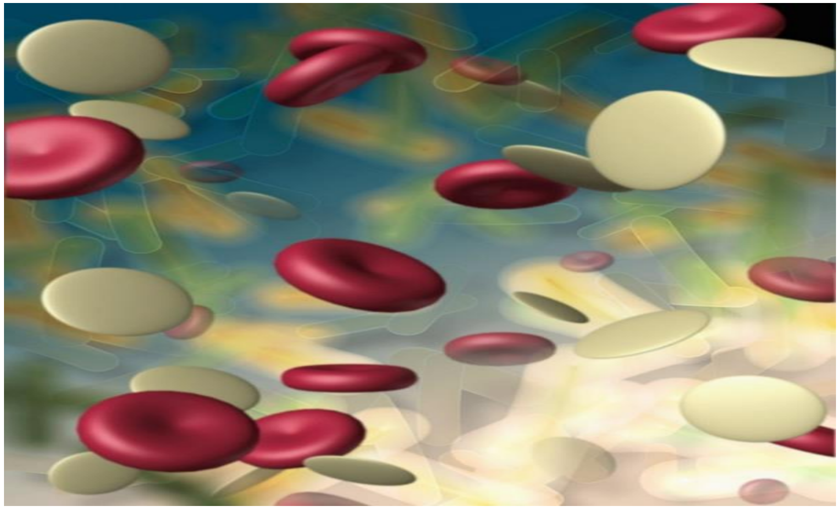
What happens in the body?



- In normal people, the immune system forms antibodies to fight against infections.
- In people with lupus, the immune system become overactive (like a bad allergic reaction) and produces a different types of antibodies.
- These antibodies attack the person’s own organs causing organ damage.



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Factors to consider in lupus

- Lupus usually appears between the age of 15-45.
- Lupus is much more common in females compared to males. Ratio 9:1
- Lupus is characterized by episodes of flares (when people feel very ill) and periods of remission (when people feel well and back to baseline).
- Flares are unpredictable, can be triggered by periods of stress or infections.

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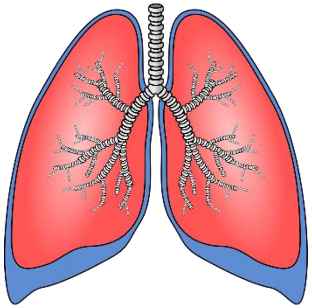
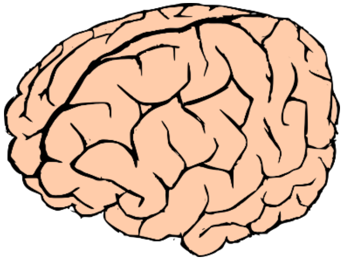
Organs affected by systemic lupus

Skin

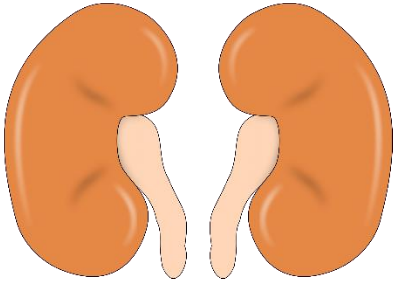


Lungs

Joints

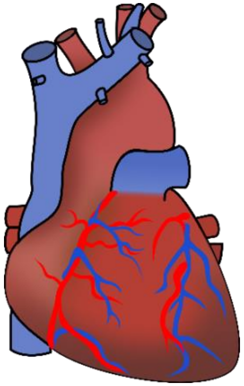


Brain



Kidneys

Gastrointestinal tract



Heart

Signs and symptoms of lupus

- Fatigue
- Weight loss
- Facial rash
- Joint pain
- Swelling of the legs
- Headache
- Oral ulcers
- Photosensitivity
- Fever
- Chest pain
- Shortness of breath
- Color changes of the fingers and toes
- Seizures
- Blood clots
- Stroke

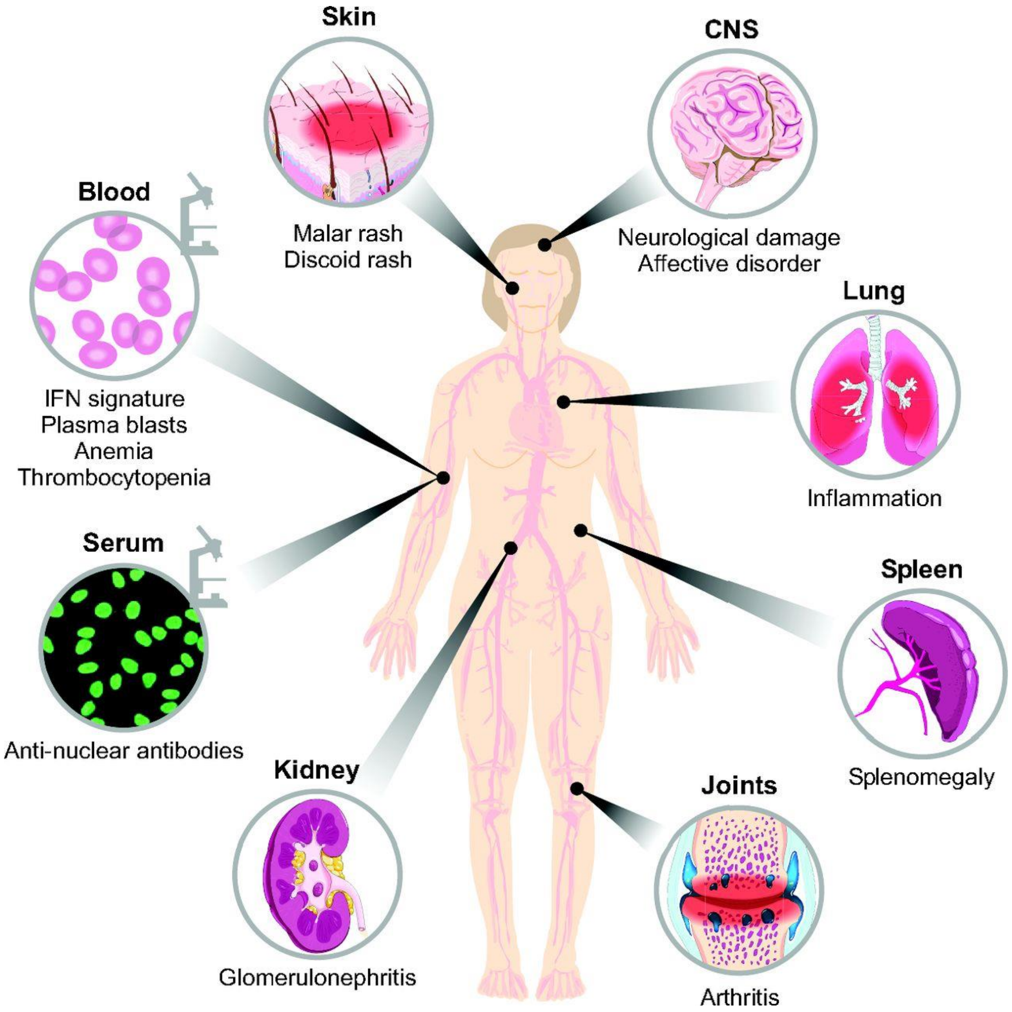
Types of lupus

- There are five types:

  1. Systemic lupus erythematosus
  2. Discoid lupus
  3. Drug induced lupus
  4. Neonatal lupus
  5. Overlap syndrome

Systemic lupus erythematosus

- “Systemic” means any organ of the body can be affected .

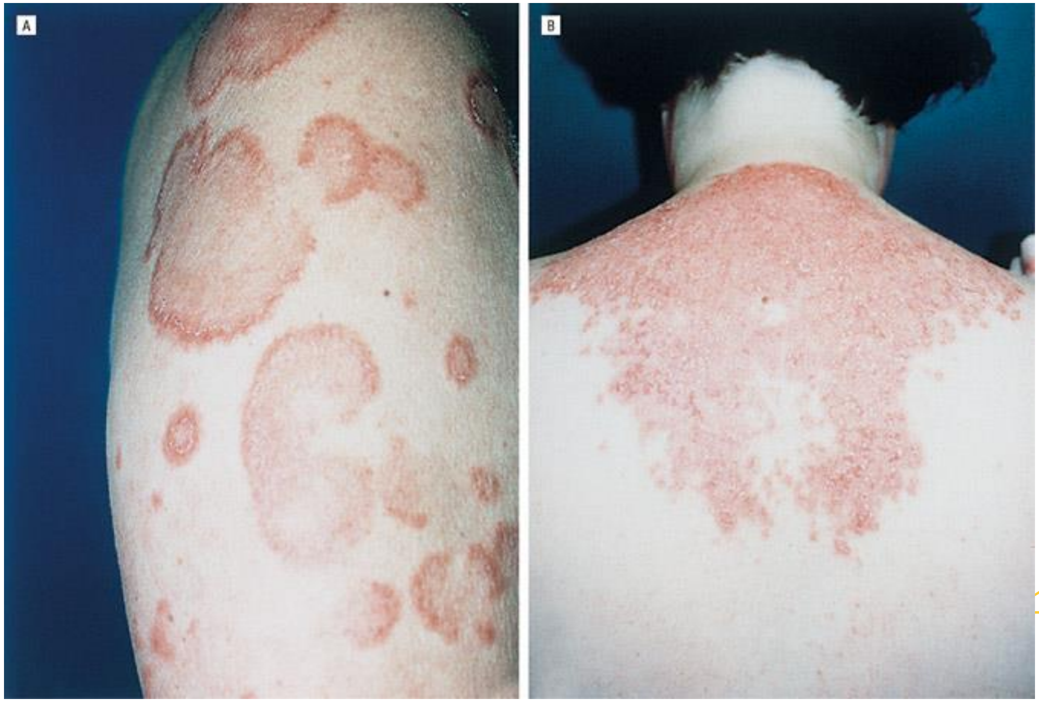


Discoid lupus

- Localized to the skin.
- Rash is red, itchy, typically heals with a scar.
- Usually on the head, cheeks and ears.
- Can affect the scalp and scars with bold patches.
- Most people don’t develop systemic lupus.
- A small percentage can progress into systemic lupus.

Drug induced lupus

- Caused by a medication triggering the immune system.
- Symptoms: rash, joint pain, muscle pain and fever
- Symptoms typically resolve after the offending drug is discontinued.



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Neonatal lupus

- During pregnancy, antibodies can cross the placenta to the fetus.
- Babies can be born with a rash, usually resolves by 8 months.
- Some babies can have slow heart rate that may require a permanent pacemaker placement.

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Overlap syndromes

- Lupus can be associated with other autoimmune disorder like:

  1. Lupus and rheumatoid arthritis

  2. Lupus and scleroderma

  3. Lupus and myositis.

Diagnosis of lupus

- Great masquerader.
- Lupus can be very challenging to diagnose.
- Lupus can take 4-6 years and up to 3 physicians before it gets diagnosed.
- Symptoms can be vague and not initially suggestive of any diagnosis.
- Diagnosis of lupus requires a good history, physical exam and blood work.

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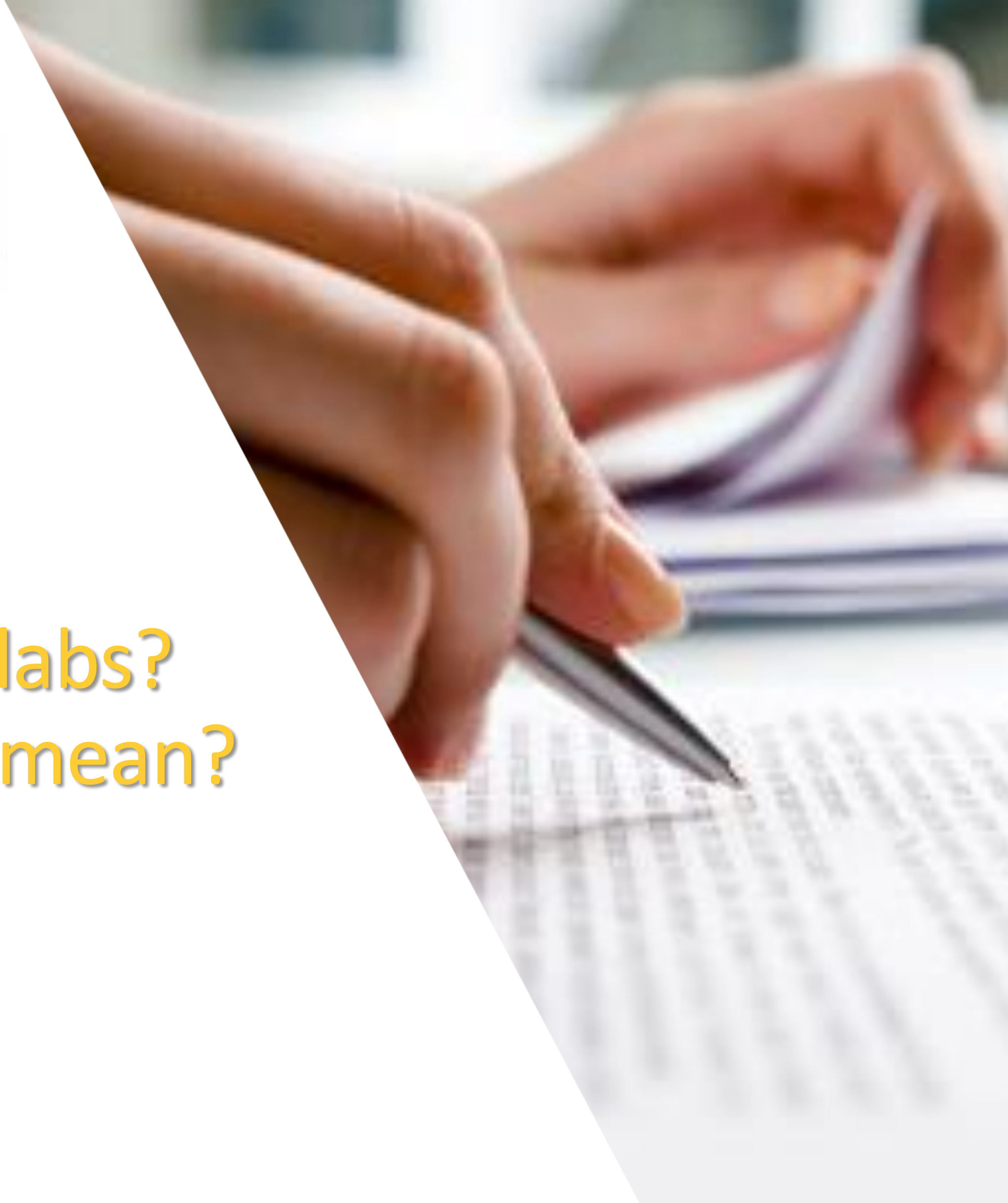
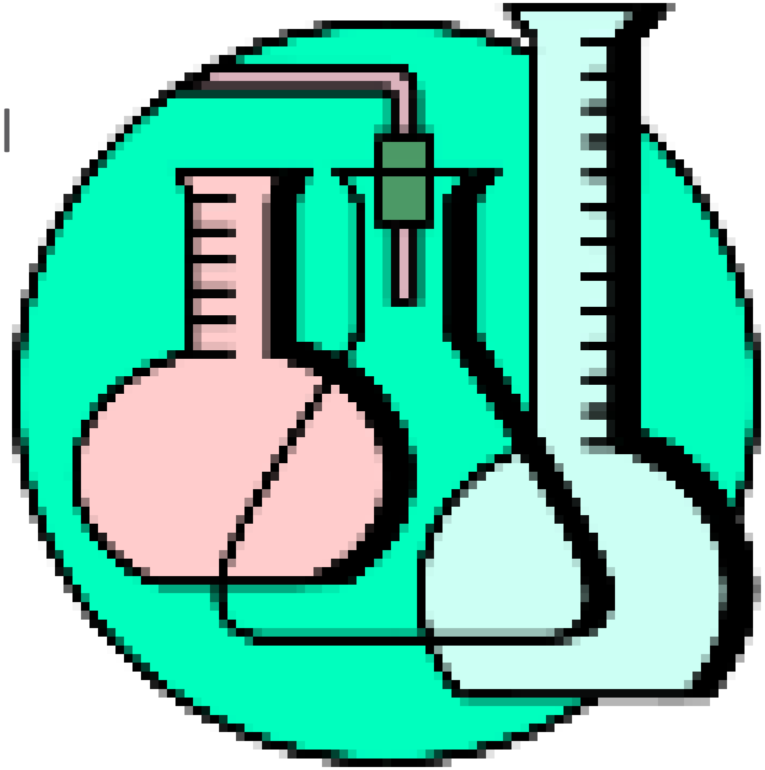


Why all those labs? What do they mean?

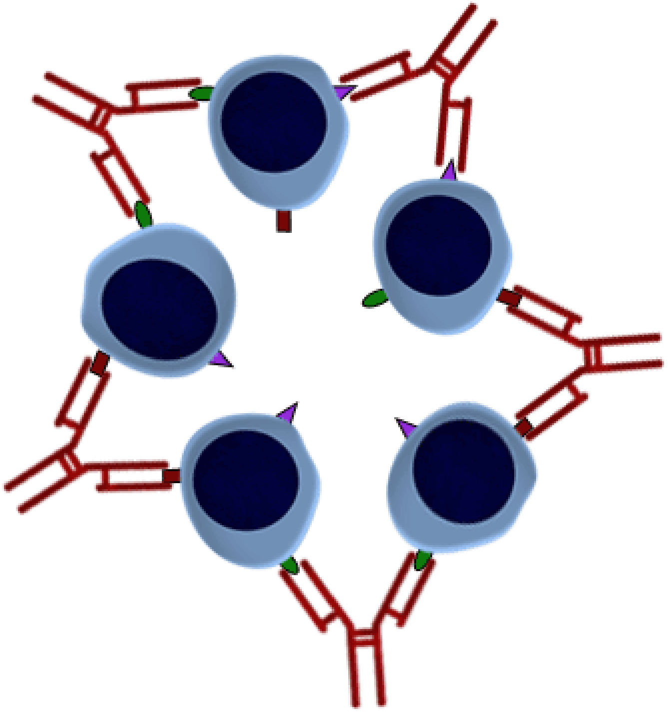
Initial work up

- Autoimmune disease panel
- Comprehensive metabolic panel
- Complete blood counts
- Urinalysis
- Urine protein/creatinine ratio



Autoimmune disease panel

- Antinuclear antibodies (ANA)
- Anti-double stranded DNA (Ds-DNA)
- Anti Smith antibody
- SSA antibody
- SSB antibody
- RNP antibody
- Anti Sl70 antibody
- Anti-histone antibody
- Anti Jo1 antibody
- Anticardiolipin antibody
- Lupus anticoagulant
- Beta2glycoprotein antibody
- Complement C3 and C4



Anti-nuclear antibodies (ANA)

False positive ANA:

- If the person has another autoimmune disease
- If a relative has an autoimmune disease
- Medications
- Age
- Viral infections

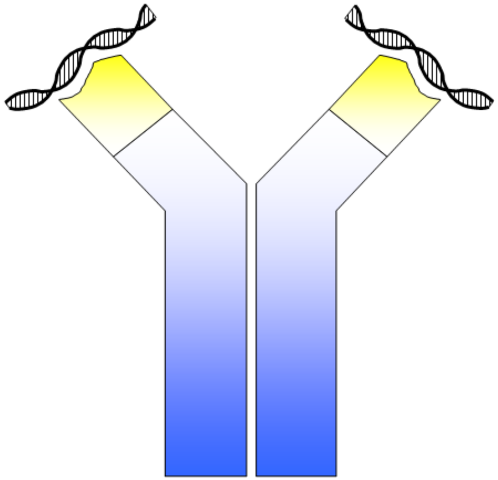
→ ***+ ANA does not always equal lupus.***

ANA is positive in 99 % of patients with systemic lupus.

→ ***If someone has a negative ANA, he/she is unlikely to have lupus.***

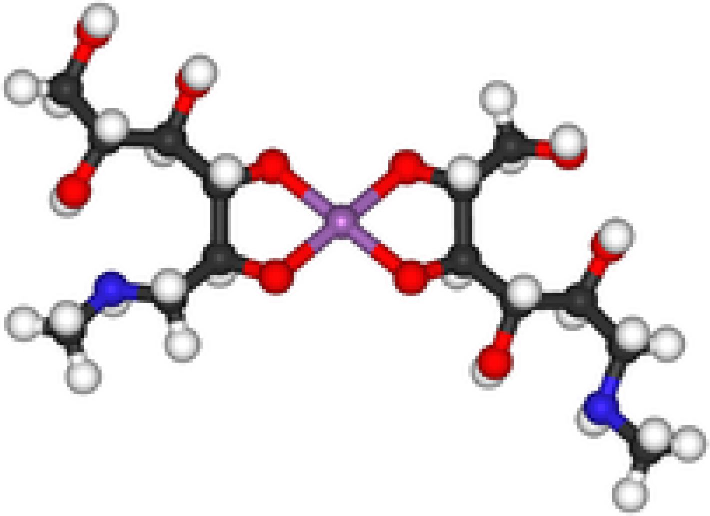
Double-stranded DNA (Ds-DNA) antibody

- Specific to lupus.
- Usually elevated when the disease is active
- Can be a measure of disease activity.
- Should be negative or low titer when the disease is controlled and not active.



Complements C3 and C4

- Usually low when the disease is active (consumed during the immune process).
- Can be a measure for disease activity.



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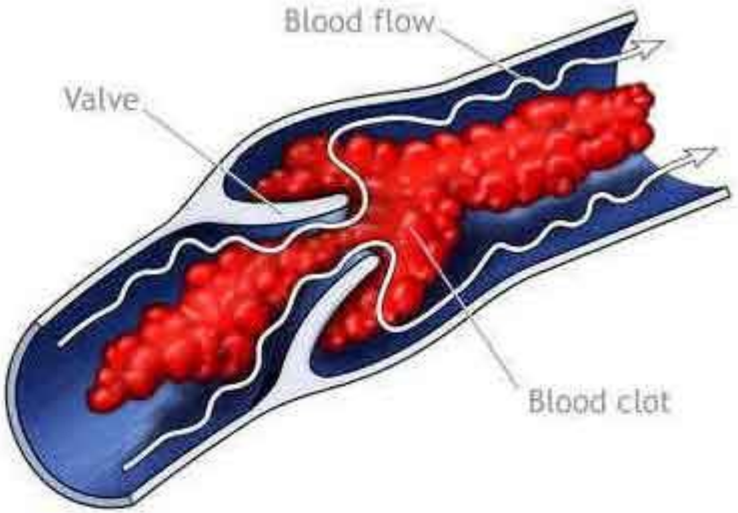
Clotting risk tests

- Systemic lupus can sometimes be associated with a clotting disorder called antiphospholipid syndrome or APS.

- APS is defined by the presence of positive laboratory tests and history of blood clots or miscarriages.

- There are 3 laboratory tests to detect APS:
  1. Lupus anticoagulant
  2. Anticardiolipin antibody
  3. Beta2glycoprotein 1

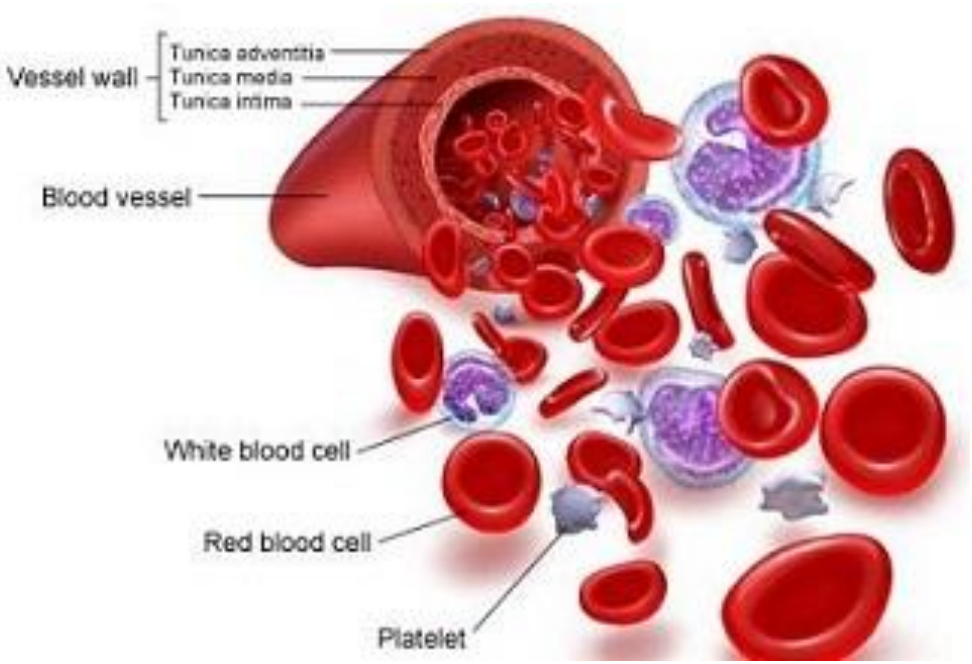


Comprehensive metabolic panel

- Includes:
  - Sodium
  - Potassium
  - Glucose
  - BUN
  - Creatinine
  - Albumin
  - AST/ALT (liver enzymes)
  - Albumin

Complete Blood Counts

- Includes:
  - White blood cells
  - Hemoglobin
  - Hematocrit
  - Platelet count



Urinalysis

- Protein
- Urine glucose
- Blood in the urine
- Leuko-esterase
- Nitrates
- Casts

Protein/creatinine ratio

- Used to monitor kidney function and can detect early kidney involvement.
- If the ratio is elevated, it can suggest that the kidneys are spilling protein and could be inflamed (lupus nephritis).
- In some instances, a 24 hour urine collection might be needed for more precise measure of proteinuria (protein leak)
- Infection should be ruled out before considering the diagnosis of lupus nephritis.
- If there is a concern for lupus nephritis, a kidney biopsy

is usually indicated to confirm and classify the diagnosis.

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How often should my laboratory tests be repeated?

- Usually laboratory tests are checked every 3 months to assure that all parameters are within normal limits.
  - DsDNA
  - Complement
  - Complete blood count
  - Comprehensive metabolic panel
  - Urinalysis
  - Protein/creatinine ratio

- If patients are in flare and feel sick or if there is a concern that a medication is causing a side effect, the blood work monitoring might need to be done more frequently.

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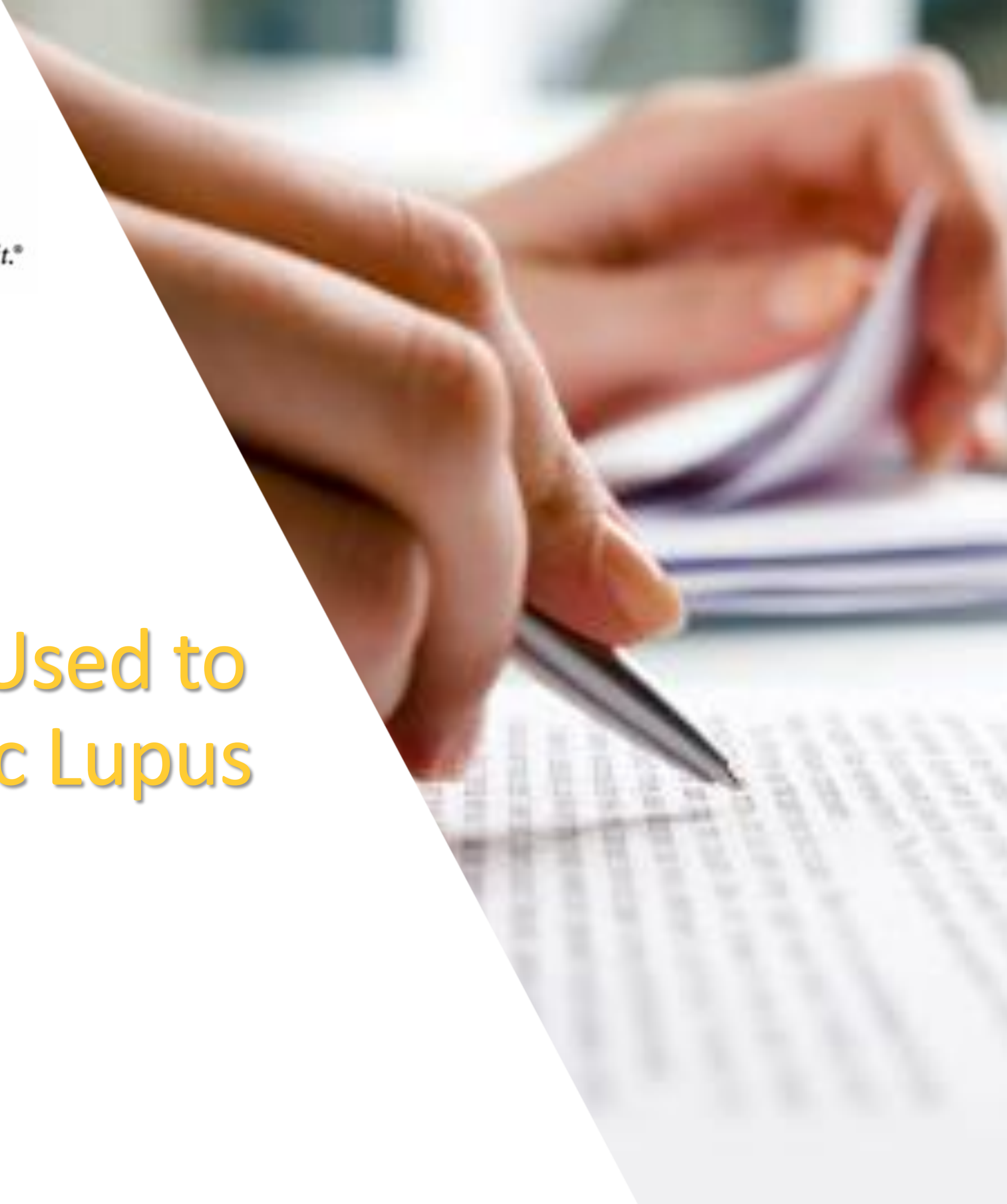

Medications Used to Treat Systemic Lupus

Medications

- Nonsteroidal anti-inflammatory drugs (NSAIDs) like Ibuprofen, Motrin, Aleve, Naproxen …
- Corticosteroids like Prednisone or Kenalog.
- Antimalarial drugs like Plaquenil (Hydroxychloroquine) or Quinacrine.
- Immunosuppressive medications like Mycophenolate (CellCept), Azathioprine (Imuran), Methotrexate, Leflunamide (Arava), Cyclophosphamide (Cytoxan), Cyclosporine and Tacrolimus.
- Biologics like Belimumab (Benlysta) or Rituximab (Rituxan).

Nonsteroidal anti-inflammatory drugs (NSAIDs)

- Can be used for fevers, headaches and joint pain.
- Should be used with caution in patients with high blood pressure, heart disease or kidney disease.
- NSAIDs can also increase the risk of bleeding, should be avoided in people on anticoagulation or with gastric ulcers.

Corticosteroids

- Corticosteroids are medications like Prednisone, Prednisolone, Medrol, Solumedrol and Kenalog.
- They can be administered topically, orally, intra-muscular, intra-articular or intravenous.
- Usually 1st line therapy in very active disease and flares, often life saving.
- Should be weaned to the lowest effective dose because of the significant toxicity “Frenemy”.
- Potential side effects: Hypertension, diabetes, osteoporosis, cataract, easy bruising, weight gain, insomnia and infections.

Antimalarial medications

- Plaquenil (Hydroxychloroquine) or Quinacrine (needs to be made by a compounding pharmacy).
- During the WW II, soldiers that took Plaquenil for malaria prophylaxis had less joint pain.
- Can be effective with skin and joint symptoms.
- Sometimes helps also with constitutional symptoms (fatigue and aching).
- Very few side effects, mostly retinal toxicity → importance of regular eye exams.

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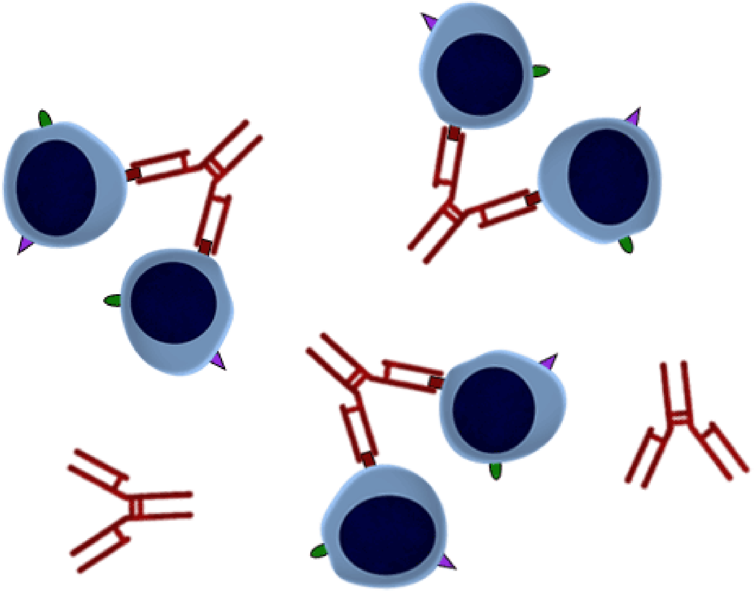
Immunosuppressive Medications

- Work by suppressing the immune system.
- Indicated when the disease is moderate to severe
- Used if corticosteroids can not be weaned off or are not tolerated or needed to treat lupus.
- Multiple classes:
  - Mycophenolate (CellCept)
  - Azathioprine (Imuran)
  - Methotrexate
  - Leflunamide (Arava)
  - Cyclophosphamide (Cytoxan)
  - Cyclosporine (neural) and Tacrolimus (prograf).
  - Different side effect profile depending on the class but all have an increased risk of infections and require frequent blood work monitoring.

Biologics:



- Belimumab (Benlysta):

  - First approved drug for lupus in 50 years.

  - Used for skin disease, joint pain and fatigue.

  - Given IV monthly.

- Rituximab (Rituxan):

  - Not FDA approved for lupus but approved for refractory disease or hematologic manifestations.

  - Given IV every 6 months divided in 2 doses 2 weeks apart.

Adjunctive measures

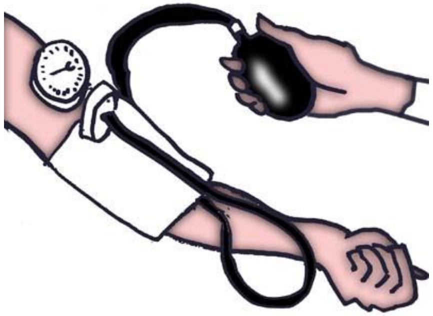
- Patients with lupus should avoid the sun because it can trigger a flare.
- If exposed to the sun, they should apply sun screen of an SPF >30 and broad spectrum every 2 hours.
- Patients with lupus should undergo age appropriate cancer screening through gynecologic exams and mammograms
- They should also have regular dental and eye exams to avoid complications from lupus medications

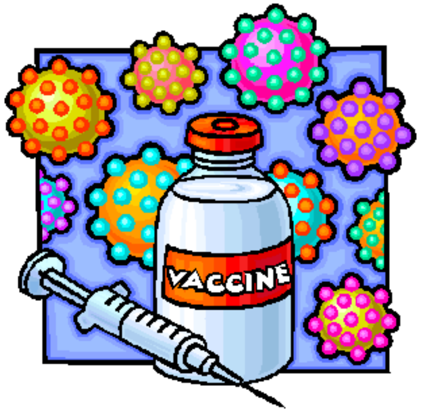
Adjunctive measures (continued)

- It is important to get the appropriate vaccinations to prevent infections. However, live vaccines should be avoided in the setting of chronic immunosuppression.

- Patients should consult with their physicians about getting calcium and vitamin D to prevent bone loss (especially if they are on chronic corticosteroids).

- Patients with lupus should monitor their blood pressure and blood sugar regularly (especially is on chronic corticosteroids).





Life style modifications

- It is critical for patients with lupus to remain active and maintain a regular exercise activity program.

- Well balanced diet.
- No sugar sweetened beverages
- More fruits and vegetables
- All these measures should help prevent other conditions like high blood pressure, diabetes, obesity and high cholesterol.

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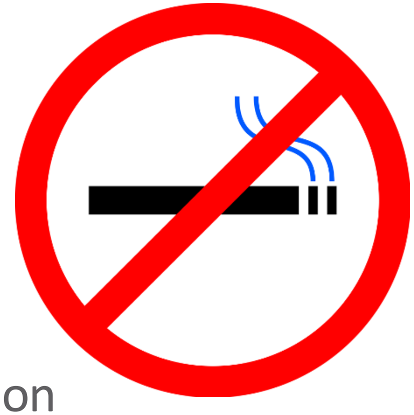
Habits To Change



- Smoking: makes lupus symptoms worse and lowers medication efficacy.

- Sun exposure: triggers flares

- Stopping medications without consulting with the doctor.

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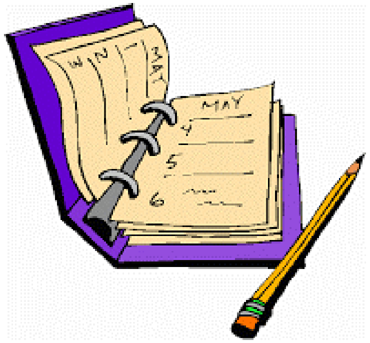
How to navigate the health care system

Suggestions



- Consider a diary where you can keep track of all your symptoms, triggers, history of medication use and side effects, hospitalizations, etc…..

- Visit your doctors office regularly, even when you are feeling well.

- Be prepared for the office visit, write down questions.

- Be honest with your provider. Don't keep back information (supplements, herbs, OTC)

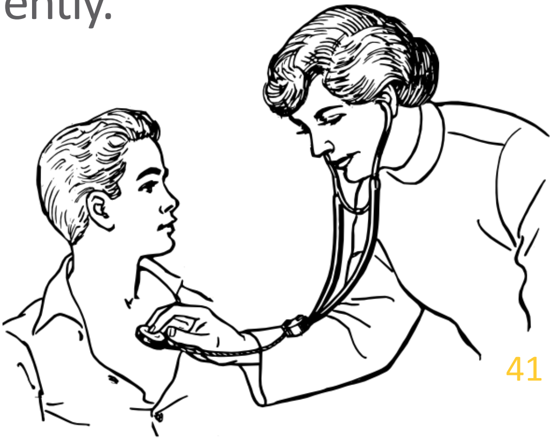
- Share your concerns.

Suggestions for your visit (continued)

- Consider bringing a family member or a friend with you to the office.
- Name and information of other specialties to help communicate your current condition and make a combined decision.
- Take notes during the visit.
- Ask for clarifications.
- Summarize your understanding of the plan at the end of the visit.

How often should I see my doctor?

- Intervals between visit are variable depending on how active the disease is and how well medications are tolerated.
- Typically, patients that have stable (quiet) disease should visit their providers every 3 months even if they are feeling well to keep track on the progression of the disease (can be silent) and the frequency of the blood monitoring.
- If patients are sick (flare) or having side effects from some of their medications, they might need to be seen more frequently.
- Your doctor will decide about the frequency of your office visits.



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Stress and Lupus

Stress and Lupus

- Studies have shown that stress can trigger lupus flares.
- The immune system becomes more active during episodes of stress.
- Stress can be due to a major event, daily activities, or dealing with a chronic illness.
- Stress can also make hypertension and diabetes difficult to control.
- Stress can cause depression!!

Suggestions to manage stress

- Make a list of priorities.
- Stick with your plan.
- Make time for fun
- Massages, meditation.
- Discuss with your heath care provider.
- Find support groups.

How can I obtain more information about lupus?

- Discuss with your health care provider.
- Read more about lupus by going to the library or use reliable internet websites.
- Local lupus societies like the lupus society of Illinois.
- http://www.lupusil.org

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Questions?