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.
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.
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.
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.
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.
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.
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.
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 Scl70 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.
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

- 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.
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.
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.
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 if they are 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.
Habits To Change

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

• Sun exposure: triggers flares

• Stopping medications without consulting with the doctor.
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 visits are variable depending on how active the disease is and how well medications are tolerated.

- Typically, patients with 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.
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 health 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
How to put in your own Photo:

Go to 'View - Slide Master'.

Go to 'Insert - Picture'.

Browse to the image you would like to place. Image should be 1024x768, 1200x900, or other 4:3 aspect ratio.

Select image and click OK.

Scale to full screen size if necessary.

Click image, go to 'Format - Send to Back'.

Questions?