

RESEARCH IN RHEUMATOLOGY

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Why is patient involvement in research important, and what are clinical trials?

The research process is essential to understanding and expanding knowledge about a disease, such as lupus. Understanding the mechanisms of a disease allow scientists to identify targets for drug discovery.

Potential drugs are rigorously tested in the laboratory to gather information on how the compound works in the body, how it should be administered, dosing, potential side effects, drug-to-drug interactions, and effectiveness. Only the most promising compounds transition from laboratory testing to human clinical trial.

Clinical trials are carefully designed studies that test the safety and efficacy of a specific medical treatment.

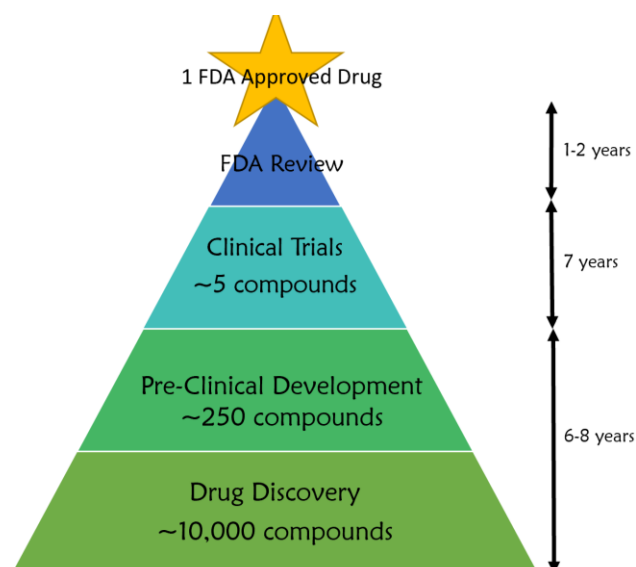
Testing an investigational new drug in clinical trials is the primary way that researchers find out if a new treatment or intervention is safe and effective in people. The Food and Drug Administration (FDA) requires a multi-phase clinical trial process before deciding if a medical treatment can be used for the broader patient population.

- **Phase 1:** The main goal is to find the highest dose of a new treatment that can be given safely.
- **Phase 2:** This phase tests whether a new treatment is effective.
- **Phase 3:** If a new treatment has positive results in Phase 1 and Phase 2, then it goes on to Phase 3 clinical trials, which compare the safety and effectiveness against the current standard treatment. Phase 3 studies may also test the long-term safety and efficacy of the new treatment.

Approximately 13% of drugs in clinical trials will eventually receive approval from the Food and Drug Administration (FDA). It takes approximately 10 years for a new treatment to go from development to being available for a prescription.

Why should I participate in clinical trials?

- **To help other patients!** Trials are essential in not only identifying new treatments but also understanding the disease more fully.
- **To gain access to cutting-edge treatments.** Trials allow patients to access new treatments when traditional treatments have been unsuccessful.
- **To receive specialized care.** Involvement in clinical trials allows patients the opportunity to receive expert medical care, since doctors conducting clinical trials are often specialists in the disease area.



UW RESEARCHER SPOTLIGHT: Dr. Sladjana Skopelja-Gardner



Dr. Skopelja-Gardner obtained a PhD in Immunology at the Dartmouth College School of Medicine. She joined the Elkon Lab at UW Rheumatology in 2017. She investigates the immunologic link between skin sensitivity to ultraviolet light and kidney disease in lupus. We asked her a few questions about her work:

Why is it important to study sun sensitivity in lupus?

The flare-like quality of lupus makes living with this condition frustrating -- sometimes, a flare can occur just after a single day in the sun. Sensitivity to ultraviolet (UV) light affects ~70-85% of lupus patients, resulting in skin disease and often leading to the worsening of systemic disease symptoms, including kidney disease, which is a major cause of morbidity for lupus patients.

What is the goal of your particular study?

Our goal is to understand why skin in lupus patients is more sensitive to UV light and how skin reacts to sunlight. We use the latest technology to study the skin at different time points relative to UV exposure. This approach will help us understand the underlying differences between lupus and healthy skin (i.e. what predisposes lupus patients to skin disease). Additionally, we will find out how lupus skin responds to UV light immediately after exposure (hours) and later on (weeks) and compare these responses to those of healthy people. This will allow us to identify relevant biological targets to both prevent and treat adverse responses to sunlight in lupus.

What can lupus patients do to engage in research?

We are always looking for patients to volunteer to participate in our research studies. We cannot answer these difficult and important questions without the help of our lupus patients! It is our patients that provide us with not only the biological samples but also the human perspective when trying to understand how lupus skin responds to UV light.

DOCTOR'S TIPS: Sun Protection & Photosensitivity in Lupus

By Sarah H. Chung MD

Excess exposure to ultraviolet (UV) rays can be a major trigger for lupus flares. Photosensitivity usually refers to a skin response after UV exposure, but fever, fatigue, and joint pain can also indicate photosensitivity, too. It's thought that the damage caused to cells by UV light is implicated in the abnormal processing of dead and dying cells in lupus. Here are some tips to stay sun smart:

- **Recognize photosensitivity.** Take note of UV exposure around the time of any typical lupus symptoms: did these symptoms worsen after significant sun exposure? Know that other non-lupus conditions (i.e. polymorphous light eruption, chronic actinic dermatitis, etc.) can look like photosensitivity, so it's important for your doctor to consider other possibilities too.
- **Seek "broad-spectrum" sunscreens that block both UV-A and UV-B light.** UV-A and UV-B are two types of UV rays that reach Earth, and both can be problematic for lupus patients. Older sunscreens historically block only UV-B light, so take a look at the bottle and choose sunscreens that block both types.
- **You may need more than just sunscreen.** Only clothing can block long-wave UV-A light; glass blocks UV-B but not UV-A light. Wear sun-protective clothing, broad-brimmed hats and sunglasses, and consider tinting for car windows or window film for high-exposure areas in your home.

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Find available studies on our website at rheumatology.uw.edu/research/clinical-trials

You can contact our research group directly at RheumResearch@medicine.washington.edu or talk to your rheumatologist about getting involved in our research!