What to Consider Before Joining Lupus Clinical Trials

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Know Your Rights as a Participant in Lupus Clinical Trials

If you're considering enrolling in a clinical trial that evaluates lupus medication, you may have concerns about your safety, privacy, and whether or not the process (and your medical records) is confidential. For this reason you should be aware of your rights, because you are protected by The Patient's Bill of Rights when you get involved in a clinical trial.

The Patient's Bill of Rights

Clinical researchers believe that you should be fully aware of the therapy, your medical choices, the risks and benefits, and possible consequences of getting involved in the study. Here is a quick review of your rights when deciding to volunteer in a research project:

1. You have the right to receive safe, considerate and respectful care from the medical team, based on your personal beliefs.
2. The medical records and data collected during the study and related to your care is confidential as permitted by laws applied to the clinical research trial.
3. It is your right to know the doctor who is in charge of your medical care during the research study, and also to receive information about the diagnosis, treatment and outcomes from the doctor in a way you can fully and easily understand.
4. You have a right to receive all necessary information related to the trial in order to be able to provide informed consent before the treatment starts. For example, a healthcare professional will take the time to explain to you the treatment, possible risks and benefits associated with it, alternative options available, and other relevant information (exceptions to this right can be made in case of an emergency).
5. Your health condition will be closely monitored on a regular basis, and if you suffer from other conditions besides lupus the doctor will treat these conditions as needed during the study. In case you suffer from pain, a doctor will assess and treat the pain.
6. You will know in advance when your next appointments and follow-ups are booked and what to do after the study is completed.
7. You have the right to refuse to get involved in the research and refuse a treatment — for any reason, before or after the trial has been started. You also have the right to be informed of the consequences of refusing the treatment (in which case you may be dismissed from the study).

Every volunteer involved in lupus clinical trials has the right to receive a medical report or summary from the medical team, a report that can be sent to the referring MD. For more details about your rights you can visit The NIH Clinical Center Patient Bill of Rights.

Other Considerations

Besides understanding your rights, you should also talk to the doctors to fully understand your clinical study responsibilities. This will be included in the consent form you need to sign prior to entering the study. For example, you will have to commit to undergo various screening tests and regular follow ups during the duration of the study.