Linda Willies, lupus patient and LFATGCC Board Member discusses her 10 year experience in a clinical trial

Lupus

Participating in Clinical Trials



Thoughts and emotions surrounding deciding to participate in a clinical trial

- Why should I contemplate joining a clinical trial?
- What about the bad reputation that clinical trials have gotten in the past? Should I be scared?
- How do I know if I will qualify?

Who should you talk to when making a decision? Where should I turn?

- What if my doctor is not participating in the clinical trial
- Where can I turn to find out more about what clinical trials are available in my area?



Tips on talking to family and friends about participating in a clinical trial

- How do I explain what a clinical trial is to my family and friends?
- How do I explain to a child about clinical trials?



What should I expect to do once I decide to join a clinical trial

- Consent Forms
- Physical Examinations
- Labs & Test
- What will the cost be for me?
- What happens if I am excepted?

Visits

- Facility (Dr. Office, infusion clinic, hospital)
- How often is the procedure
- How long does it take?
- Will I need someone to help take care of me?

Possible side effects

- How do I know if I am having a reaction to the medication?
- When do I know that my side effect is serious enough to call my physician or nurse?

- What should I expect once the clinical trial is underway and things are going well?
 - Build relationships with the clinical trial staff
 - Become an advocate for clinical trials
 - Educate others about the safety and benefits of clinical trials