You’ve Got the Power...If You Use It

Questions to ask your researcher and yourself before enrolling

August 1, 1997 By Stuart Timmons

Since we started, our exit interviews of patients who’ve been in clinical trials show the number one reason they enroll is they thought they were going to get the drug, and it was going to work for them." So says Dr. Stephen Miles of UCLA’s HIV Care Clinic. Not only do all studies, by their very nature, disappoint some hopefuls, but pre-made decisions tend to be poor ones. In an attempt to help volunteers think carefully, some clinics even have policies requiring participants to take the informed consent form home, read it with an adviser or even initial every page.

Volunteers are often unaware that they have more power than anyone else in monitoring a trial. Frequently, contracts signed between a pharmaceutical company and a test site will restrict the freedoms of the trial administrator. But the volunteer is always free to raise any question at any time. If you don’t get a complete answer, you may want to consider discontinuing the trial. (Remember to be practical and considerate -- neurotic pests don’t invite thoughtful engagement.)

Here’s a list of questions to ask your trial administrator or yourself before and even after jumping in.

- Have you made your mind up in advance or after careful questions and study?
- Do you have other options than to take this trial?
- Is this trial your only access to clinical care?
- Will participation in the study incur any costs to you?
- Is this trial advertising itself as treatment or as ideal for patients who meet certain criteria? (If it is, watch out: Though some trials offer proven therapies, trials, by nature, involve unknowns and risks.)
- Is the study offering any monetary compensation? (If so, again watch out: Often, the higher the compensation, the higher the risk.)
- How will the investigators update you about developments during this trial?
- How many trials have been done on this drug?

- Do you understand the consent form? Is it in your native language, and is someone available to translate medical terms and their implications?
- Are you taking enough time before signing up? Don’t be hurried.
- Has the investigator taken this drug? The look on his or her face -- and the ensuing dialogue -- may offer unique insights on what effects the drug will have on your body.

For information or counseling on participation in clinical trials, or for a copy of the booklet Should I Join an AIDS Drug Trial?, call AIDS Treatment Data Network at 800.734.7104, or 212.260.8868 for New York City residents. Questions about your rights in trials can be directed to the FDA’s Office of Special Health Issues at 301.827.4460. Copies of relevant federal regulations and reports are available from the federal Office for Protection from Research Risks at 301.496.7005 or through the fax-call service at 301.594.0464 or on the Web at www.nih.gov/grants/oprr/oprr.htm.

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