

ASK THE DOCTOR

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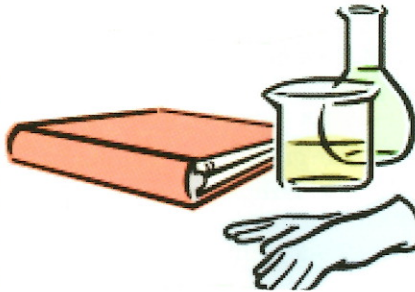
What are the risks and benefits of taking part in research studies?

Q: I have a particular disease, and I know that a medical school in my community recruits people to participate in research studies. I'm wondering if I should volunteer for one of these studies. What do I need to know?

A: There are two good reasons to consider volunteering for a study: the study might help others, and it might help you. There also may be risks to you, in some types of studies. As with anything in life, you will need to balance the possible benefits to you and others against the possible risks. To do that, you need to be given a clear idea of what the benefits and risks are.

Every study for which you might volunteer has been carefully designed: there is a detailed written plan specifying every question you might be asked, the kind of physical examinations that might be performed, the tests that might be ordered, and any treatments you might receive. This detailed plan has been thoroughly reviewed by a committee called an Institutional Review Board (IRB). The committee includes doctors, nurses, researchers, and members of the community – none of whom are involved with the study. Their job is to determine whether the study has acceptably low risks for the participants. No study can proceed unless the IRB has approved it.

Some studies (called observational studies) simply collect very detailed information from you on an ongoing basis, but don't ask you to do anything that would put you at risk. It was studies like this that discovered that people who smoked had a much higher risk of lung cancer. Other studies (called clinical trials) require you to have a particular "intervention." The intervention might be a diagnostic test, like a colonoscopy, or a treatment – a medicine, a surgical procedure, or another therapy.



Whatever type of study you participate in, you will be given a written description of what the study will involve for you. The completeness and accuracy of that description will have been reviewed and approved by the IRB. If you have any questions after reading the document, the study staff must answer those questions. You cannot be enrolled in the study unless you sign the document, which is called giving informed consent. If you do choose to participate, you can withdraw at any time. Being in the study won't change your regular medical care: you'll still see your usual doctor. In addition, typically the study (and its treatments) costs you nothing, and you may even be paid for participating.

Many of my patients have volunteered to participate in medical studies. None I know of have experienced a complication, but it can happen. Some of them have benefited: their condition improved because of the experimental treatment used in the study.

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SFNE SUPPORT GROUPS

Maine

Maine Support Group
Contact the SFNE office at 978-887-0658
for more information on forming a group.

Massachusetts

Boston Support Group
Boston University
Medical Center - Shapiro Building
First Floor Conference Room
Meets the 3rd Sunday
of every month
Group Leader: Carol Taylor
774-233-0558, cvsing@comcast.net

Fall River Support Group
Meets the 3rd Tuesday of every month
6:30 - 8:30pm
Co-Leaders: Donna Bernier
Donnabdab2@hotmail.com
774-488-6775
Christine T. Maroney, 508-675-4152

North Shore Support Group (Topsfield)
Meets 2nd Wednesday of most months
Group Leader: Roberta Mauriello,
781-324-7426

Worcester Area Support Group
Meets once a month on Sunday
Group Leaders: Nancy Velleco
and Mary Ann Persson
Please contact Nancy for specific dates.
508-869-2997

New Hampshire

Granite State Support Group
(Hampstead)
Meets last Saturday of the month
Co-Leaders: Carla King
978-884-4866
granitestate@scleroderma.org
Jean Chapman
chappybear@charter.net

Vermont

Burlington Vermont Support Group
(Williston)
Meets the 2nd Wednesday of most months
Group Leader: Blythe Leonard
802-878-0732, b.leonard@myfairpoint.net

Brattleboro Area Support Group
Now meets second **Wednesday** of each month
Brattleboro Memorial Hospital, 6:00 - 7:30pm
Group Leader: Ilene Wax
802-464-5847
ilene wax@gmail.com

Connecticut

Greater Enfield Support Group
Group Leader: Sharon LeDue
860-741-5028 or EnfieldCT@scleroderma.org