

# Clinical Trials Research - What does it offer?

## Guide to Clinical Research Trials

Clinical trials are research studies in which people may volunteer to participate. A clinical study is designed to answer specific scientific questions. An ethics board reviews a clinical study before researchers are allowed to initiate their study. Participants are selected based on certain criteria. A participant chooses freely to participate or not after reviewing the possible risks and benefits of participation. Some studies will pay for people to participate in their research.

A common question people with brain injury and their families ask is: "Where can I find information on clinical trials for brain injury?" There is not just one answer to this question. Unlike specific diseases, such as AIDS and cancer, there is not a single location where the majority of brain injury clinical trials are listed. A possible reason for this is the nature of brain injury and the level of public awareness. Brain injury is not "one disease." There are distinct stages that occur during the recovery process. For instance, during the acute stage, pharmacological (medication) interventions are geared towards minimizing additional adverse medical consequences. During the post-acute stage, persons are medically stable, but may have cognitive, physical, or emotional impairments.

Locating clinical trials on brain injury can be challenging. The following information offers suggestions for searching for clinical trials and a listing of a sample of clinical trials currently recruiting volunteers.

Considerations when searching for clinical trials:

- There are no guarantees. You may search the clinical trial databases-- and find nothing. There is no guarantee that there is something out there that will help your particular situation. However, you may find that these sites can point you in the right direction.
- The presence of a clinical trial does not automatically mean you will qualify to participate, receive the treatment being offered, benefit from the treatment being offered, or "be cured" of brain injury. Keep in mind, this is research, and at the present time there is no cure for brain injury. Researchers set up a study because they have reason to believe, but are not sure about, an intervention and need more information.
- Discuss the information with your doctor before participating. Research trials are designed to be as risk free as possible, but by their very nature, research trials are looking into the unknown. Take the time to read through ALL research material, and ask questions. A good resource to read is a guide developed by the National Institutes of Health. You can go here to read this guide: [Volunteer Patients and Clinical Research](#). This Guide describes the basics of clinical research, what the different "phases" mean in clinical trials, and questions you may want to ask before choosing to participate in a research study. Consider the potential benefits and potential drawbacks of participating in a clinical study. Discuss the information you find with your doctor.
- Participation in clinical trials is a personal choice and may not be for everyone. Choosing to participate or not to participate is an individual decision that should be respected.

There are several resources worth reading that cover the basics of research trials. These include:

[Guide to Clinical Research](#) This brochure was developed by the Warren Grant Magnason Clinical Center. This Center is where the National Institutes of Health conduct much of their clinical research. The brochure describes the basics of clinical research, what the different "phases" mean in clinical trials, and questions you may want to ask before choosing to participate in a research study.

**The "Bill of Rights" for Clinical Center Patients.** The Bill of Rights for Clinical Center Patients concerns the care you receive, privacy, confidentiality, and access to medical records. This bill was developed for use in clinical trials from the "Patient Bill of Rights" developed by the [National Hospital Association](#).

### **Searching the Web for Research Trials**

- Search for local universities or large rehab centers. These are places that might be running clinical trials. Sites listed below will help you identify some of the major research centers associated with Universities.
- Some websites offer personal clinical trials notification, and will email updates on trials relevant to a person's interest.
- Some websites require user registration prior to a site search. Most sites only require you to register with an e-mail address.
- Some websites may ask for your mailing address, name, area of interest, etc. before they allow you to gather research trial information. Make sure you read their privacy policy before doing so.

The list of clinical trials provided below is not comprehensive- it is intended to be a helpful resource for persons starting to look for clinical trials.

- **ACURIAN** [www.acurian.com](http://www.acurian.com) This website features the capability to develop a personal profile of information. Registration is not required to search the database.
- **CenterWatch** [www.centerwatch.com](http://www.centerwatch.com) Center Watch offers a listing of clinical trials and a personal clinical trial notification option.
- **Clinical Trials** [www.clinicaltrials.gov](http://www.clinicaltrials.gov) This site is provided by the [National Institutes of Health](#), in collaboration with the [National Library of Medicine](#) and [Federal Drug Administration](#). The site contains a large amount of clinical trials primarily conducted in the USA and includes 70 other countries.
- **RehabTrials.org** [www.rehabtrials.org](http://www.rehabtrials.org) A listing of rehabilitation trials developed by Kessler Medical Rehabilitation Research and Education Corporation (KMRREC). Their stated mission: "RehabTrials.org is dedicated to the promotion and support of clinical trials in medical rehabilitation research." This website lists clinical trials focused on rehabilitation.
- **Research Match** [www.researchmatch.org](http://www.researchmatch.org) - a not-for-profit effort that brings together researchers and people who are willing to learn more about research studies via a secure and convenient online web portal. It is a free and secure registry that has been developed by major academic institutions across the country who want to involve you in the mission of helping today's studies make a real difference for everyone's health in the future. [added 2011]
- **TrialsCentral** [www.trialscentral.org](http://www.trialscentral.org) This site offers a listing of clinical trials, as well as a resource section that offers educational materials.
- **Veritas Medicine** [www.veritasmedicine.com](http://www.veritasmedicine.com) This is a searchable site of clinical trials and treatments. A personal clinical trial notification option informs a registered user of possible opportunities to participate.
- **The Warren Grant Magnuson Clinical Center** [www.cc.nih.gov](http://www.cc.nih.gov) 800-411-1222 or 1-866-411-1010 (toll free TTY). The Warren Grant Magnuson Clinical Center has listings for National Institutes of Health (NIH) funded studies. This site is where many NIH research studies are carried out.

- **The Pharmaceutical Research and Manufacturers of America (PhRMA)** [www.phrma.org](http://www.phrma.org) represents research-based pharmaceutical and biotechnology companies. The site provides information about prescription medication in development and available from member companies. A second website: [www.pparx.org](http://www.pparx.org) lists patient assistance programs available through PhRMA's member companies. These programs can assist people in obtaining prescription medication for free or at reduced costs.

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