

The National Institute of Neurological Disorders and Stroke (NINDS) Clinical Research Collaboration (CRC) is a new opportunity for physicians and patients who want to learn about or participate in research studies of neurological diseases. The NINDS CRC is designed to help patients, family members, and others quickly find actively recruiting research studies for which they or someone they know may be eligible. It will give physicians the opportunity to perform NINDS research in their own offices and will provide the latest updates and results from research studies.



NATIONAL INSTITUTE
OF NEUROLOGICAL
DISORDERS AND STROKE
CLINICAL
RESEARCH
COLLABORATION



Connecting research
to communities



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Institute of Neurological Disorders and Stroke

NIH Publication No. 06-5763
March 2006

NINDS
CRC
CLINICAL RESEARCH COLLABORATION
Connecting Research to Communities



How Does it Work?

Physicians who join the **CRC** and complete the certification requirements will be able to enroll a patient in an NINDS-sponsored clinical trial and provide screening and follow up throughout the study period. In some cases, physicians can choose to refer patients to a study being conducted at another site and then remain involved in the study while still providing the patient's standard care.

Patients and others who join the **CRC** will be notified when new studies begin recruitment so they can consider becoming a study participant.

All persons who join—whether they are actively participating in a trial or are just **CRC** members—can elect to receive information and updates on selected clinical trials, as well as general information about neurological disorders and new research discoveries. The **CRC** website will serve as a communications hub, where patients, doctors, and the public can search for trials in progress, trials being planned, and ongoing research.

Participating physicians will receive study-specific training in addition to the general training—good clinical practices for research, human subjects protection, **HIPPA**—that will be part of the initial **CRC** certification process. **CRC**-certified physicians will be offered free **CME** credits for some training.

There are no fees required for participating and **CRC**-certified physicians who enroll or follow patients in a study will receive compensation.

How Do Patients and Physicians Join the **CRC**?

The easiest way to sign up is to join online at www.nindscrc.com. By joining the **CRC** now you will be notified when the **NINDS CRC** becomes operational and the features described above are available to you. You can also join by mail (fill in the attached card and send it to the **NINDS CRC** Operations Center) or by phone (1-800-305-7811).

How Will **CRC** Data Be Stored?

All information from **CRC** members will be stored in databases at the Operations Center of the **NINDS CRC** located at The **EMMES** Corporation in Rockville, Maryland. Only a few authorized personnel at the Operations Center can see the information, and the staff will never give personal information to other organizations without your permission. Outside reviewers will regularly evaluate systems at the Operations Center to ensure that the data are secure.

What is the **NINDS**?

The **NINDS** is a component of the National Institutes of Health (**NIH**), the major source of funding for health research in the United States. The **NINDS** conducts and supports research on brain and nervous system disorders. One of the more than two dozen research institutes and centers that comprise the **NIH**, the **NINDS** has been conducting and supporting research on neurological disorders for more than 50 years.

How Can I Contact the **CRC**?

NINDS CRC Operations Center
401 N. Washington Street, Suite 700
Rockville, MD 20850-1737

- E-mail: ninds-crc@ninds.nih.gov
- Phone: 1-800-305-7811
- Fax: 1-800-588-3404



Thank you for your interest in the **NINDS** Clinical Research Collaboration (**CRC**). To register, please fill out the attached card and mail it to the **NINDS CRC**.

Preferred method of contact: Phone Fax E-mail Regular Mail

Title: _____

Name: _____

Address 1: _____

Address 2: _____

City, State, Zip: _____

Phone: _____

Fax: _____

E-mail: _____

Send to: NINDS CRC Operations Center
401 N. Washington Street, Suite 700, Rockville, MD 20850-1737