
Summary of Pilot Activities

NINDS



CLINICAL RESEARCH COLLABORATION

Connecting Research to Communities

Anne S Lindblad, PhD
**Director NINDS Clinical Research
Collaboration Operations Center**
The EMMES Corporation

AIMS

- **Facilitate participation in NINDS sponsored research by both patients and MDs**
- **Expedite NINDS sponsored research recruitment**
- **Recruit a broad range of participants, particularly minorities**
- **Minimize cost of infrastructure, to reduce per participants costs**



NINDS CLINICAL RESEARCH COLLABORATION

CONNECTING RESEARCH TO COMMUNITIES

[Find a Research Study](#)

[Why Participate in Research](#)

[Additional Information](#)

[Become a Participant](#)

Contact Information

1-800-305-7811

ninds-crc@ninds.nih.gov

Email:

Password:

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[Become a Participant](#)

Join the NINDS CRC

- Search the actively recruiting studies.
- Become a CRC participant.
- Obtain additional disease information and study related results faster.
- Physicians can complete CME credits.
- Become CRC certified and conduct research in their offices.

Welcome to a new opportunity for physicians and patients who want to learn about or participate in research studies of neurological diseases. This service will help people quickly find actively recruiting research studies for which they may be eligible. It will give physicians the opportunity to perform NINDS research in their own office and will provide the latest updates and results from research studies.

The National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH), an agency of the U.S. Department of Health and Human Services, has created the NINDS Clinical Research Collaboration (CRC) to help people join research studies to develop new and better treatments, faster.

Find a Research Study

[Check to see if you or someone you know is eligible for a study.](#)

Become a Participant

[Anyone can join \(patients, physicians, family, friends\) and receive free information.](#)

Post a Research Study

[NIH grantees can apply to post their studies.](#)



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[News and Events](#) | [My Profile](#)

Welcome Dr. Anne Lindblad! Join a CRC study and participate in research in your office. You will be paid for your time and can earn free CME for training.

[\[Learn More\]](#)

See below for studies you can conduct in your office.

[Insulin Resistance Intervention after Stroke \(IRIS\) Trial](#)

By participating in this randomized trial of 3,136 study subjects, you will be investigating a new stroke prevention strategy using - *pioglitazone* - for prevention of recurrent stroke and MI after ischemic stroke or TIA. Pioglitazone is an agent that reduces insulin resistance, which is linked to increased risk for stroke and other vascular diseases. Certification for this study takes about 5 hours. You will receive free CME credits. You will be paid at least \$5,500 per subject for completing all study follow-up requirements.

[\[About This Study\]](#)

[\[Earn IRIS Certification\]](#)

[Carotid Occlusion Surgery Study \(COSS\)](#)

By participating in this randomized trial of 372 study subjects, you will be investigating the prevention of subsequent ipsilateral ischemic stroke (fatal and nonfatal), over a two-year period, in patients with symptomatic carotid artery occlusion who undergo surgical anastomosis of the superficial temporal artery to the middle cerebral artery. Certification for this study takes about 6-7 hours and you will receive free CME credits. You will be paid at least \$5,000 per subject for completing all study follow-up requirements.

[\[About This Study\]](#)

[\[Earn COSS Certification\]](#)

NEWS & EVENTS

[Join us for breakfast \(April 15th 6:45 AM - 8:30 AM\) and Level I training \(April 15th 1:00 PM - 3:00 PM\) at the AAN Annual Meeting. Click to learn more...](#)

[Sign up for the NINDS mailing list.](#)

[\[MORE\]](#)

My CERTIFICATIONS

Do research in your office.

Certification is a few steps away.

[\[LEARN MORE\]](#)

Registered Physicians

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Level I

Training Information		
	Status	Date Completed
Good Clinical Practice	COMPLETED	12/04/2007
Human Subjects Protection	COMPLETED	12/07/2007

Current Federalwide Assurance Information

FWA #	Status	Expiration Date
FWA77878787	Active	05/16/2008

Level II

Study Specific Certification Information

Study : [IRIS](#)

Certification Status : InProgress

Date Certified :

Clinic Name	Clinic Type	Site Status
Medical College of Wisconsin	Enroll/Follow-up	In Progress

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[\[MORE\]](#)

My CERTIFICATIONS

	Status
Level I	Certified
IRIS	InProgress

[\[VIEW DETAILS\]](#)

CME Summary

Did you know that the CRC offers FREE CMEs?

[You have completed 0.0 CME hrs since you joined the CRC.](#)

Done
Internet

Why Participate in Research

Additional Information

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Online Programs:

▲ Date ▼	▲ Topic ▼	▲ Title ▼	Program Slides	▲ Post Test/Evaluation ▼
12/21/2007	Neurology	<u>Treatment of Acute Ischemic Stroke: Where Do We Go From Here?</u>	Download PDF	Available 12/21/2007 00:00:00
08/01/2007	Neurology	<u>ALS 2007: Symptomatic Management and New Therapeutic Options</u>	Download PDF	Available 08/01/2007 00:00:00
07/11/2007	Neurology	<u>Atherosclerotic Carotid Artery Occlusion: Prognosis and Treatment</u>	Download PDF	Available 07/11/2007 00:00:00
06/06/2007	Neurology	<u>Emerging Concepts in Epilepsy</u>	Download PDF	Available 06/06/2007 00:00:00
05/02/2007	Neurology	<u>Deep Brain Stimulation for Parkinson's Disease</u>	Download PDF	Available 05/02/2007 00:00:00
03/07/2007	Neurology	<u>What's New in Stroke? The "Top 10" Studies for 2005-2007</u>	Download PDF	Available 03/07/2007 00:00:00
02/07/2007	Neurology	<u>Principles of Clinical Research: Why We Do What We Do</u>	Download PDF	Available 02/07/2007 00:00:00
01/03/2007	Neurology	<u>Recognition and Treatment of Early Parkinson's Disease</u>	Download PDF	Available 01/03/2007 00:00:00
12/06/2006	Neurology	<u>What Are Whole Genome Association Studies (and Why Should We Care)?</u>	Download PDF	Available 12/06/2006 00:00:00
11/01/2006	Neurology	<u>What's New in Stroke? The "Top 10" Studies for 2004-2006</u>	Download PDF	Available 11/01/2006 00:00:00
08/15/2006	General	<u>Good Clinical Practice for Research: GCP Overview for Researchers</u>	Download PDF	Available 08/15/2006 00:00:00
08/15/2006	General	<u>Human Subject Protection, HIPAA, and Research</u>	Download PDF	Available 08/15/2006 00:00:00

Lunch & Learns:

▲ Date ▼	▲ Topic ▼	▲ Title ▼	▲ Registered? ▼	Course Materials	▲ Post Tes
02/06/2008	Neurology	Catamenial Epilepsy: Definition, Prevalence, Pathophysiology and Treatment	YES	Download PDF	Avg 02/06/20



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Find a Research Study

Search results for: **Stroke**[More information about Stroke](#)[Search Another Disease](#)

Protocols

The protocols meeting your search criteria are listed below. On this page you can:

- *Click on a protocol (study) title to learn more about it and search for study sites near you*
- *Answer questions to determine eligibility for a study*
- *Print a summary of the protocol and the eligibility questions you answered*

[PRINT](#)

Eligibility Questions

These questions are to check eligibility for the protocols listed on the left. As you answer questions "May be eligible" or "Not eligible" will appear in the Eligibility Status column next to the protocol title. Answer the questions to the best of your knowledge. If you do not know an answer you may leave it blank. Although you may see "May be eligible", in the Eligibility Status column, a physical examination may be required to check if all the criteria for a study are met.

Protocol Title	Eligibility Status	Check Eligibility	Yes	No
Sample Collection and Submission to the NINDS Repository, blood draw		1. Stroke or TIA less than 6 months ago?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Carotid Occlusion Surgery Study	May Be Eligible	2. Stroke or TIA less than 3 months ago?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Warfarin Versus Aspirin in Reduced Cardiac Ejection Fraction (WARCEF) Trial	Not Eligible	3. Heart failure (LV Ejection Fraction less than 35%)?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Secondary Prevention of Small Subcortical Strokes (SPS3) Trial	May Be Eligible	4. Severe mental or physical disability caused by stroke and resulting in dependency on another person	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Study Design:

Interventional,Randomized,Treatment

[TOP](#)

Study Locations:

Total Active Locations = 42

Click header to sort.

Distance willing to travel (miles):

Zip Code:

No Preference ▼

20117

GO

[TOP](#)

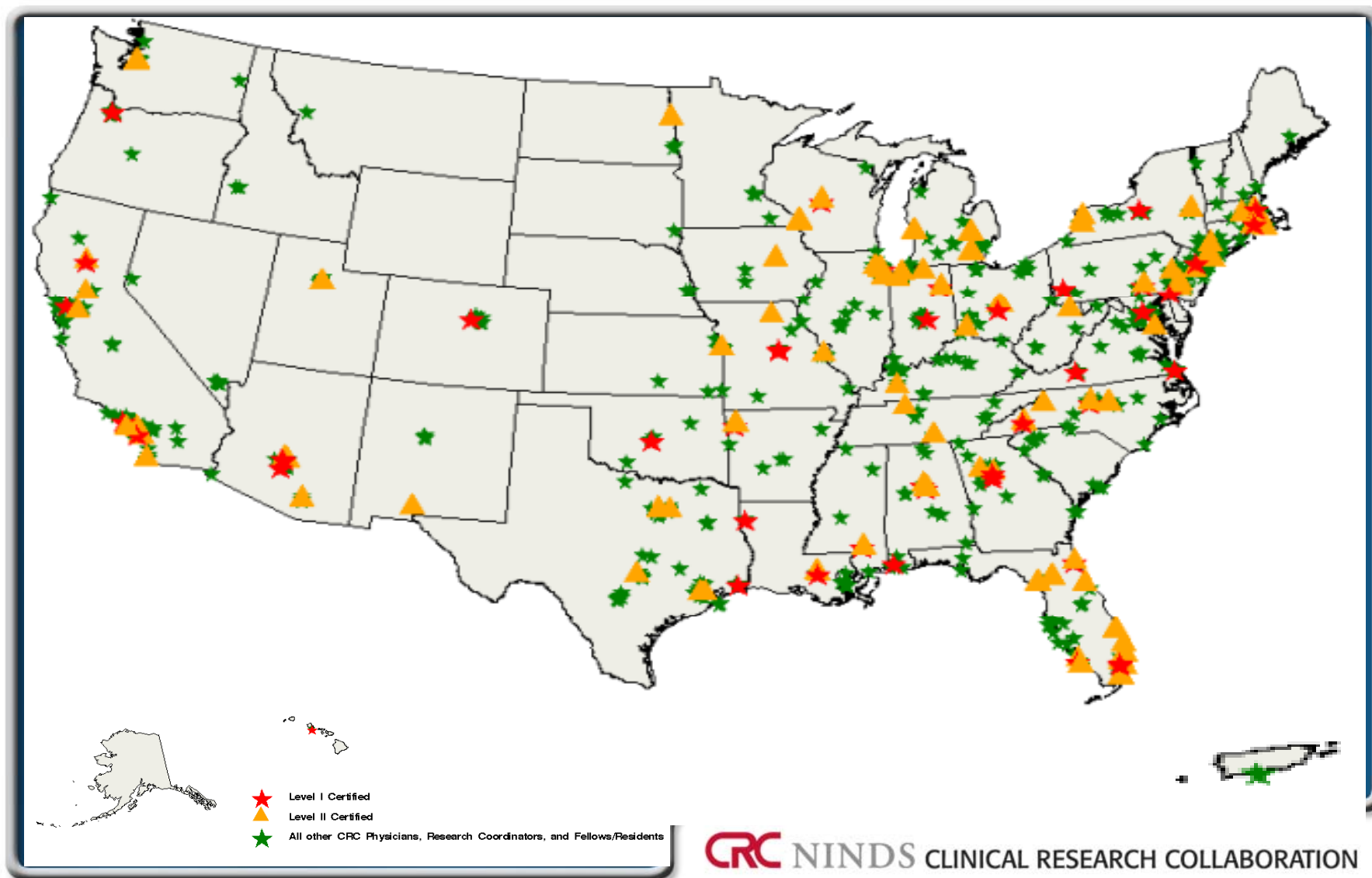
If you would like to conduct this research at your own office, contact us at 1-800-305-7811
or nindscrc@ninds.nih.gov

▲ Location ▼	▲ City ▼	▲ State ▼	▲ Level of Participation ▼	▲ Distance ▼
Johns Hopkins Bayview Medical Center <i>NINDS CRC Operations Center, 1-800-305-7811 ninds-crc@ninds.nih.gov</i>	Baltimore	MD	Enroll/Follow-up	64.0 miles
Cooper University Hospital <i>NINDS CRC Operations Center, 1-800-305-7811 ninds-crc@ninds.nih.gov</i>	Camden	NJ	Enroll/Follow-up	157.0 miles
Helen Hayes Hospital				

Recruitment

Type	Total
Total	3,545
Physician	1,298
Fellow/Resident	53
Research /Coord.	596
OHCP	459
Patient	154
Family/Friend	85
Other	900

CRC Physicians/OHCP

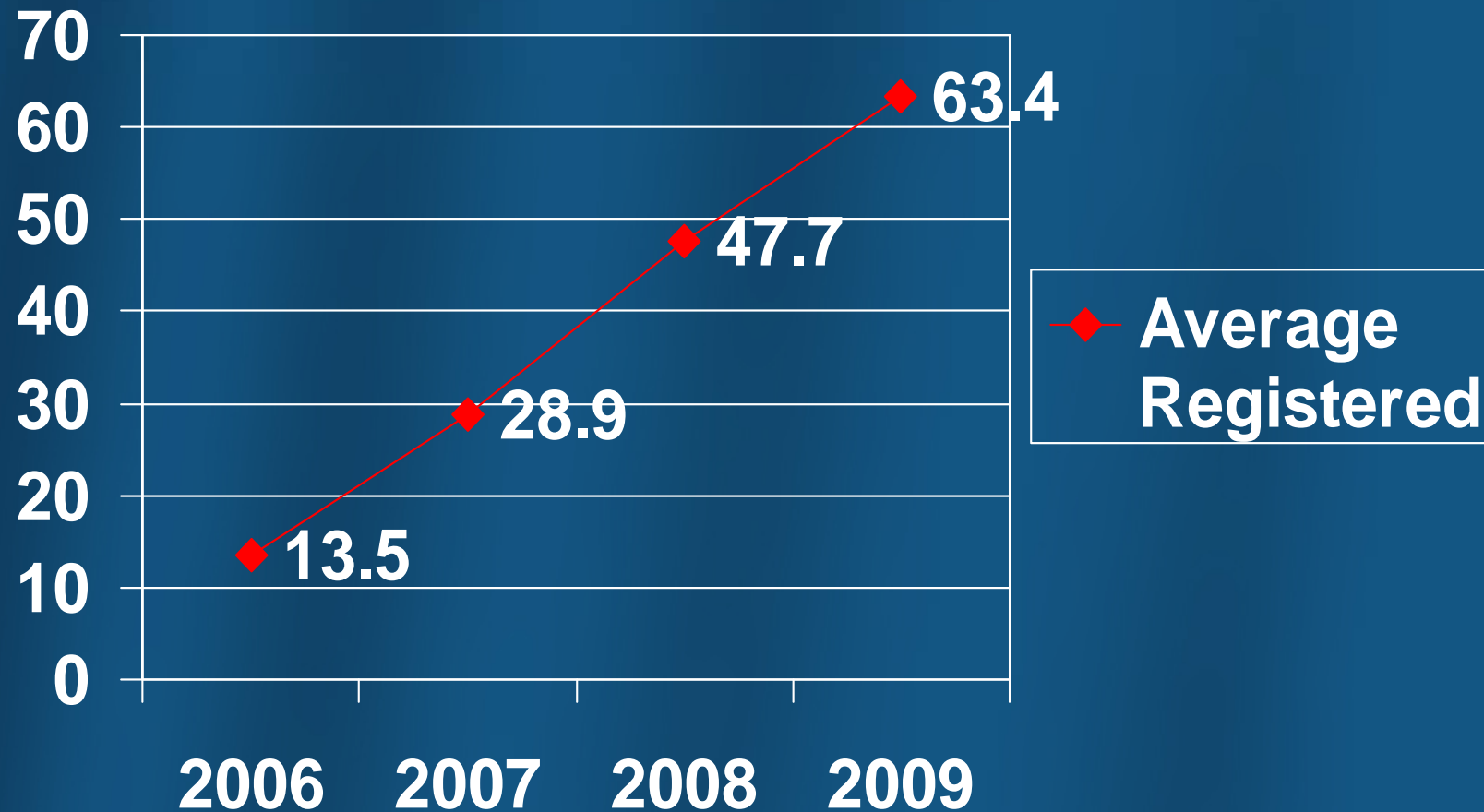


Lunch and Learn

938 attended 25 Lunch and Learns

Type	
Ever	938
1	271
2	108
3	57
4	76
5	50
6 or more	376

CME Summary



Study Portfolio

- Existing Studies
 - COSS-Stroke
 - IRIS-Stroke
 - CombiRX-MS
- New Studies
 - Genetics-Multiple Disorders/Normal Controls
 - Chronic Migraine Treatment Trial

Study Portfolio

- Physician/patient Screen and Refer (total 15 unique studies)
 - Stroke - 6
 - Myasthenia Gravis -1
 - ALS - 2
 - Epilepsy – 2
 - Migraine – 1
 - Huntington's Disease – 1
 - Parkinson's – 1
 - Other-1

Certification

Level 1

204

(GCP,HSP,FWA)

Level 2

192*(20 received certification in multiple studies)

➤ **COSS**

0

➤ **CombiRx**

0

➤ **IRIS**

22

➤ **Genetics**

30

➤ **CMTT**

160

Enrollment by Race/Ethnicity

Race/Ethnicity	Genetics N=1801	Chronic Migraine N=627
Hispanic	49%	17%
Caucasian	50%	82%
African American	29%	14%
American Indian	3%	1%
Other	18%	3%

Activation Analysis

- First CRC Contact to CMTT IRB Approval (median days)
 - Local: 155
 - Central: 100
- Time From First Contact to CMTT Contract Approval (median days)
 - Non-University: 73
 - University: 385

What Works

- Simple Studies
- Sites with Coordinators
- Fair pay for effort
- Frequent updates
- Variety of offerings (studies, lunch and learn, surveys)
- Partnerships with professional groups (AAN) and disease groups

Challenges

- Indemnification
- NIH Grant funding cycles
- University grant offices
- Private Practice Business Managers
- Mid-stream rescue
- VA, HMO, CTSA participation and collaboration

Future Potential

- Sign Master Agreements with sites and amend for each study
- Review study design with sites prior to finalizing
- Review payment with sites before activation
- Simplify training requirements; continue to reinforce
- Visit/communicate with sites early and often to build relationships

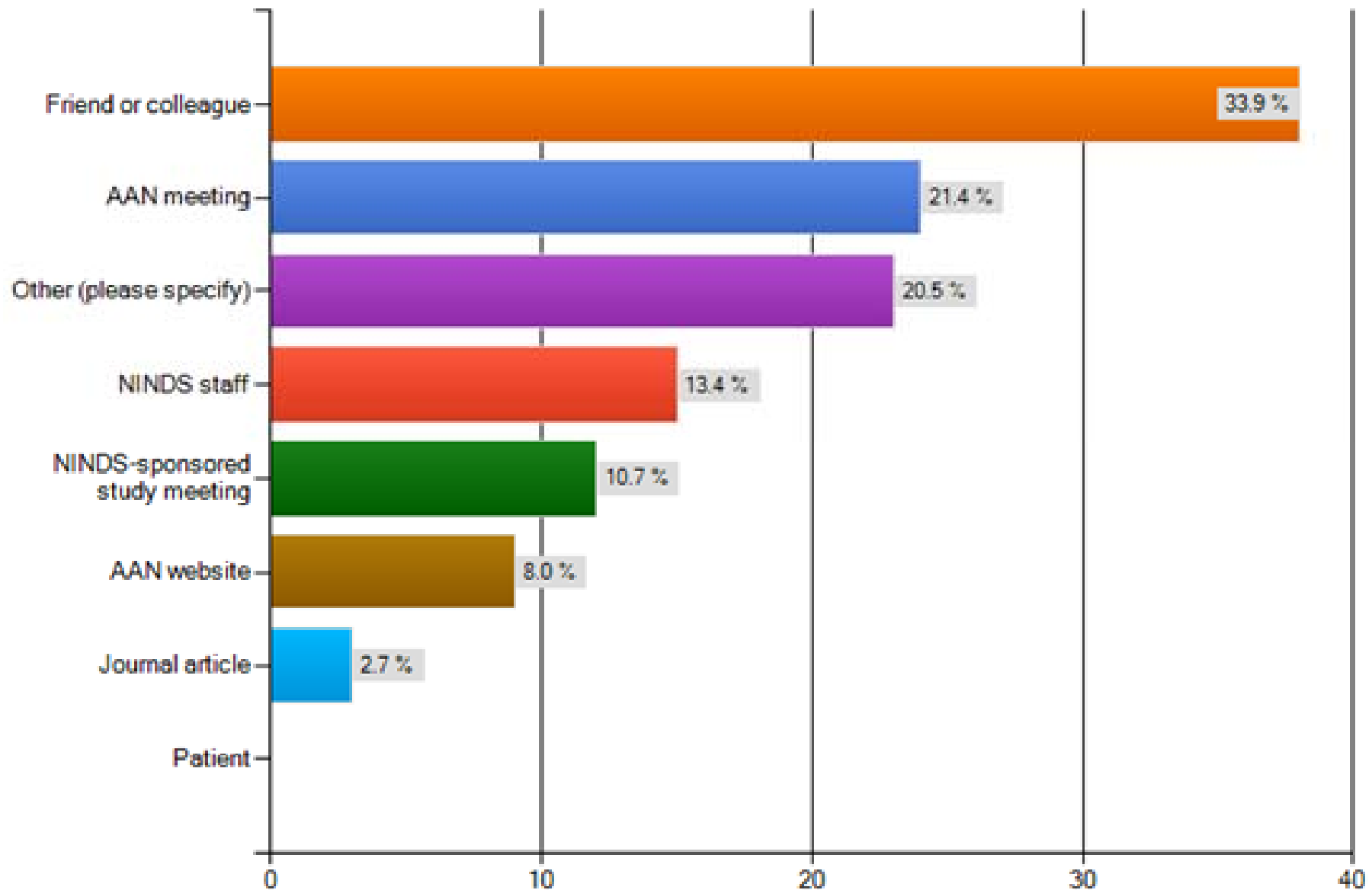
NINDS CRC

The future

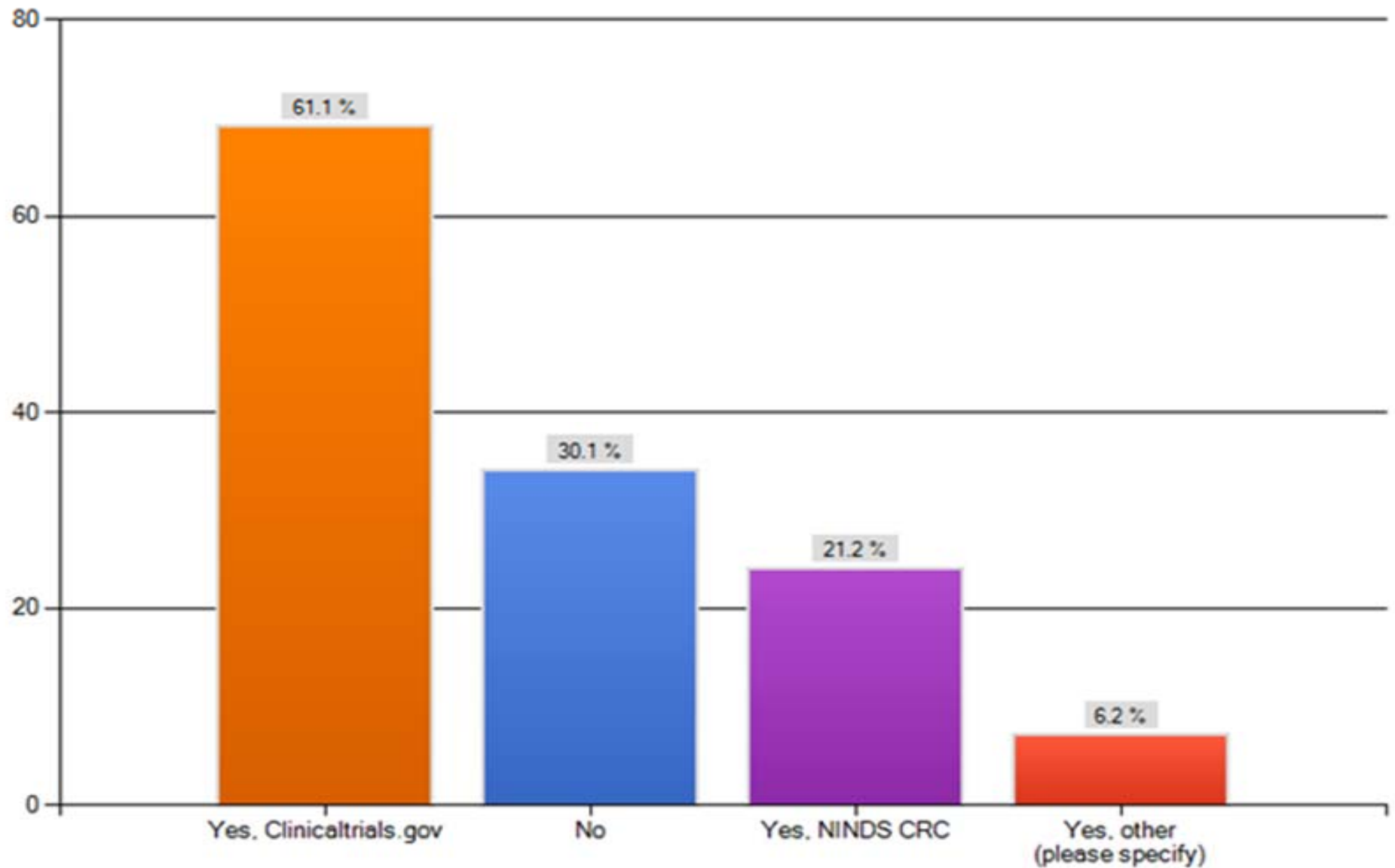
- **NINDS is using the lessons learned to pursue alternative mechanisms to enhance community participation**

THANK YOU

How did you hear about the CRC?



Gone on-line to find a research study?



Have you referred a subject due to CRC involvement?

