



## 54. Antiphospholipid Antibodies

*Last Updated: 2/15/2004*

**Q:"I've been diagnosed with anticardiolipin antibody syndrome. I'm also a prothrombin 20210A heterozygote, and have elevated homocysteine levels. Following several clots and a stroke, my local health care providers are interested in getting me seen by folks with more expertise/experience. Can you recommend where we might turn?Is there an anticardiolipin expert here in the US? Is there a center doing research or clinical trials in which I might participate?"**

A: Antiphospholipid antibody syndrome can be associated with venous clots, arterial clots, or pregnancy loss. The disorder is complex and often requires special knowledge of the laboratory tests involved (see [Q/A 21](#) and [Q/A 49](#)) so that solid clinical recommendations can be given. There is a group of physicians organized in the APSCORE project, that see patients with this syndrome and are involved in various research studies on antiphospholipid antibodies.

The APSCORE registry (ANTIPHOSPHOLIPID SYNDROME REGISTRY) is a U.S.-wide research project that started in late 2001. The goal of the registry is to:

- a. prospectively collect clinical and laboratory data on 2000 patients with antiphospholipid antibodies over a 5 year period, and
- b. to identify immunological and genetic abnormalities and mechanisms leading to thrombosis, fetal loss, and other clinical manifestations of the syndrome.
- c. In addition, the Registry will be a resource for projects aimed at improving methods of diagnosis, and evaluating more effective and safer methods of treatment and prophylaxis.

The registry is a multi-center, multi-specialty, project involving a group of leading U.S. antiphospholipid antibody syndrome investigators (rheumatologists, hematologists, neurologists, and obstetricians) at 8 academic medical centers. The study is funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

If you are a patient with antiphospholipid antibody syndrome you can contact one of the 8 participating centers and inquire about participating. These 8 centers also have specialists who frequently see patients with antiphospholipid antibodies. Clinic appointments can be made with most of these specialists. The 8 centers involved are listed below.

### APSCORE Directory

1. **Ball Memorial Hospital**  
Department of Research  
2401 University Avenue  
Muncie, IN47303-3499

Investigators:

Douglas A. Triplett, MD (Pathology)  
Jeffrey Dlott, MD (Pathology)

Study Coordinator:

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2. **Duke University**  
Division of Hematology  
DUMC 3422  
Duke University Medical Center  
Durham, NC27710

## Investigator:

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## Study Coordinator:

Betty Thames, RN  
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**3. Hospital for Special Surgery / Weill-Cornell University Medical Center**

Division of Rheumatology, Room 777W  
Hospital for Special Surgery  
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New York, NY 10021

## Investigators:

Michael D. Lockshin, MD (Rheumatology)  
Lisa R. Sammaritano, MD (Rheumatology)

## Study Coordinator:

Elizabeth Sedlis  
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**4. Johns Hopkins University**

Dept. Rheumatology  
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## Investigator:

Michelle Petri, MD, MPH (Rheumatology)

## Study Coordinator:

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**5. Morehouse School of Medicine**

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Atlanta, GA 30310-1495

## Investigators:

E. Nigel Harris, MD (Rheumatology)  
Silvia Pierangeli, PhD  
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**6. University of North Carolina at Chapel Hill**

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## Investigators:

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Stephan Moll, MD (Hematology)  
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Study Coordinator:  
Gail Buxton  
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7. **University of Texas Health Science Center at San Antonio**

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8. **University of Utah Health Science Center**

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Study Coordinator:  
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