

## What is antiphospholipid antibody syndrome?

Antiphospholipid antibody syndrome (APS) is an autoimmune disorder. Patients with APS have antibodies in their blood that, instead of fighting off infections, makes them more prone to problems such as blood clots in the deep veins in their legs or arms or in their lungs. This can also cause problems with blood clots in their arteries, causing strokes or heart attacks, as well as problems with pregnancy and miscarriages.

## How do these antibodies develop?

In most cases, we do not know why people develop these antibodies. Some patients develop them following an infection. In some patients there seems to be an increased risk for developing the antibodies, with several family members having antiphospholipid antibodies or other autoimmune problems.

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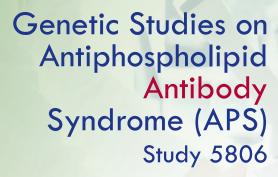
The RTDC is a member of: the Rare Diseases Clinical Research Network (RDCRN)



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### Why are we doing this study?

We know very little about why people develop APS. The goal of this research study is to identify genetic or environmental factors that may increase susceptibility to APS.

#### How can your family help?

We are looking for families where an individual has APS and one or more family members also have APS. We are also looking for families where an individual has APS and one or more family members has an autoimmune disease such as lupus, diabetes, rheumatoid arthritis, multiple sclerosis, or similar disorders.

If your family has one or more members with APS or another autoimmune disorder, your family may be eligible to join the study.

#### What does the study involve?

To participate in the study, families will be asked to agree to the following:

- A detailed family history interview conducted over the telephone or in person.
- Permission to review medical records related to the diagnosis of APS or other autoimmune disorders.
- A blood sample from the individuals with APS or other autoimmune disorder, as well as any relatives (e.g. parents, brothers, sisters, aunts, uncles etc) who are willing to give blood samples.

### What are the participation facts?

- To participate in this study:
  - You must have APS and one or more family members must have APS or antiphospholipid antibodies

OR

- You must have APS and one or more family members must have a different autoimmune disorder.
- You must sign the consent form to participate.
- All information collected is kept confidential.
- There is no cost to you. Funding for this study comes from the National Institutes of Health (NIH).
- In order to participate, you are not required to travel to Duke University Medical Center.
- Newsletters are sent yearly to individuals who participate in the study.

# What will we learn from this study?

We will learn several new things from this study:

- If there is an inherited risk for developing APS.
- If there are genes that will increase a person's risk to develop APS.
- If there are new treatments that can be developed based on the study results.



Thomas Ortel, M.D., Ph.D., of the Hemostasis and Thrombosis Center at Duke University Medical Center is the principal investigator of this research study.

#### Who do I contact?

For more information or to enroll your family in this research study, please contact the research coordinator below:

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Or, visit our website for more information: www.RareDiseasesNetwork.org/RTDC