

# Volunteer for NIAID's FUNGI Research Study APECED Syndrome



The **FUNGI study** is looking for people with autoimmune endocrinopathy-candidiasis-ectodermal dystrophy (**APECED**) syndrome.

The study is investigating:

- Why people with APECED are susceptible to fungal infections of the mouth and skin
- Why they are susceptible to developing autoimmune problems
- How to best treat the fungal infection and autoimmunity

The study will also explore genetic and immune system factors that may contribute to the condition.

**APECED** is a rare autoimmune disease caused by a faulty gene. This condition affects mainly the endocrine glands but may also affect other organs such as the liver, lungs, intestines, or kidneys. Symptoms start in childhood and may include hormonal problems and frequent infections of the mouth and the skin by the fungus *Candida*.

The FUNGI natural history study may help researchers at the **National Institutes of Health (NIH) in Bethesda, Maryland**, develop safe and more effective treatment options for patients in the future. If a study participant appears to have a genetic defect in his or her immune system, genetically related family members will also be offered participation. In addition, the study seeks healthy volunteers (those without the condition) to participate in testing.

## Where is the study taking place?

The study is being conducted at the NIH Clinical Center in Bethesda, Maryland. The NIH campus is accessible by car and public transportation.

## What does the study involve?

Participants will visit the NIH Clinical Center for the initial appointment and then approximately every 1 to 2 years. If unable to travel, participants may be able to participate by sending records and samples to NIH. Medical evaluations and procedures will vary based on a patient's disease course and may include a history/physical examination and blood, saliva, and possible tissue sampling for genetic and immunological testing. Optimal antifungal therapy may be offered for eligible patients.

## How much does it cost?

There is no charge to participate in this research study. All study-related medical care, including clinic visits and procedures, are provided free of charge.

## Will I receive payment?

Participants will be compensated for certain procedures such as tissue sampling. Transportation and other expenses may also be covered.

## Can I participate?

You may be eligible to participate if you or your child has been diagnosed with APECED syndrome or has clinical features highly suggestive of APECED syndrome.

## How do I find out more or volunteer?

If you have questions or would like more information, contact:

### Patient Recruitment, NIH Clinical Center

Toll free: **1-800-411-1222** (reference **11-I-0187**)

TTY: 1-866-411-1010 Se habla español.

Email: [prpl@mail.cc.nih.gov](mailto:prpl@mail.cc.nih.gov)

[www.niaid.nih.gov/volunteer/FUNGI](http://www.niaid.nih.gov/volunteer/FUNGI)

To learn more about this study (trial ID NCT 01386437), visit [ClinicalTrials.gov](http://ClinicalTrials.gov).

