

The logo for RepARE features the word "RepARE" in a blue, sans-serif font. A stylized graphic of a hair strand with a droplet at the end is positioned over the letter "A".

RepARE

Help us look for potential treatment options for APECED symptoms

Researchers at the NIH are trying to determine if increasing doses of an oral medication, ruxolitinib, can restore hair loss and relieve other autoimmune disease symptoms in patients with APS-1/APECED.

You may be eligible if:

- You have APS-1/APECED
- You are between the ages of 12-65 years old
- You have experienced hair loss over at least half of your scalp for more than 6 months
- You have never tried treatment or have not responded to treatment for hair loss within the past 2 months
- You are a caregiver of a patient experiencing the above

If you qualify and choose to participate, you will:

- Undergo an 8-week observation period to monitor your hair loss prior to treatment
- Receive increasing doses of ruxolitinib throughout the study period at the NIH Clinical Center in Bethesda, Maryland
- Complete quality of life assessments. Family members will also complete quality of life assessments
- Undergo lab work and imaging at the Clinical Center with some lab work also completed at an independent lab in between NIH visits

As part of the study, you will receive the study treatment and all of the study procedures at no cost to you. However, some routine lab tests completed at an independent lab will need to be covered by your insurance.

For more information, please email or call the study team:

repairestudyteam@mail.nih.gov

301-443-8341

