

LET YOUR VOICE BE HEARD

JOIN THE APS TYPE 1 (APECED) REGISTRY TODAY

APSTYPE1.IAMRARE.ORG

In 2019, with the support of NORD, the APS Type 1 Foundation launched its very own registry, making our community not only contributors to research, but actual research partners. Our hope is that researchers will look to our database as an important source of information that they cannot obtain elsewhere. Our data is one of our most valuable assets. Let your voice be heard.

THE REGISTRY

The APS Type 1 (APECED) Registry is an IRB-approved, secure database that collects information from many people with APS Type 1 and allows them to update information over time as their conditions and experiences change. Patients or their legally authorized representatives can enter important patient data into the database by completing different online surveys. These surveys can be completed at your own pace. You can start and stop by saving your progress.

WHO CAN PARTICIPATE?

Anyone with a confirmed diagnosis of APS Type 1 is eligible to participate. You may also be eligible if you have certain disease defining symptoms or a first degree relative with APS Type 1.

RESEARCHERS WE WANT TO PARTNER WITH YOU

The APS Type 1 (APECED) Registry collects disease-specific, natural history data about individuals with APS Type 1 with the goal of improving the understanding of this rare disorder and informing treatment development. **Registry surveys cover the following topics:**

- Diagnostic Information
- Demographics
- Medical History
- Quality of Life
- Clinical Trial Participation
- Misdiagnosis

If you would like to access the APS Type 1 (APECED) Registry data or create your own survey for a research project, please contact our registry administrator at registry@apstype1.org. Access to the APS Type 1 (APECED) Registry data is contingent upon project approval by The APS Type 1 Foundation and its registry advisory committee.

WHAT IS APS TYPE 1 ?

APS Type 1 (also known as APECED) is a rare genetic disorder caused by mutations of the AIRE gene. Mutations in AIRE lead to multi-organ system autoimmunity typified by three classic manifestations:

- Autoimmune Hypoparathyroidism
- Adrenal Insufficiency (also known as Addison's Disease)
- Chronic Mucocutaneous Candidiasis

APS Type 1 is also associated with many other autoimmune manifestations, including urticaria (hives), ectodermal dysplasia, tooth enamel dysplasia, chronic intestinal dysfunction, alopecia, vitiligo, pneumonitis, autoimmune hepatitis, type 1 diabetes, and gonadal failure (ovarian and testicular). While the median age of the first manifestation is age 3, new conditions can develop even after age 60.

WE ARE HERE TO ENSURE YOU ARE NOT ALONE

The APS Type 1 Foundation is a 501(c)(3) non-profit organization. Established in 2014, the Foundation's mission is to support education, awareness and research in APS Type 1. Our growing community holds a world class bi-annual international symposium and connects patients with research. Learn more on our website at www.apstype1.org for information about symptoms, diagnosis and research.



APS 1

The APS Type 1
Foundation Inc.

APSTYPE1.ORG

JOIN US TODAY

For more information, contact us at:
registry@apstype1.org

To register, visit:
apstype1.iamrare.org



THE APS TYPE 1 (APECED) REGISTRY IS POWERED BY NORD.