

# What is APS Type 1?

**APS Type 1** is not well known in the medical community and goes by several names (**Autoimmune Polyglandular/Polyendocrinopathy Syndrome Type 1** or **Autoimmune Polyendocrinopathy-Candidiasis-Ectodermal Dystrophy “APECED”**). While it has been named for its attack on the endocrine organs, it attacks many of the body’s organ systems. Patients will experience at least two of Candidiasis, Hypoparathyroidism and Addison’s Disease, but many are challenged with additional complications such as Diabetes, Autoimmune Hepatitis, Eye, GI, Lung and reproductive complications that make this condition very challenging to manage on a day to day basis.

Many people with APS Type 1 go undiagnosed for years. The stress of not knowing what is making you or your loved one sick is terrible. Even worse is the permanent damage that occurs to the body’s organs before diagnosis. Once diagnosed, the disease can generally be managed with a series of medications and rigorous oversight, but there is no known cure.

Research on APS Type 1 has the potential to help with a wide array of diseases and symptoms, due to the fact that there is a known gene that causes APS Type 1 and the syndrome itself affects so many of the body’s organs. For example, research into APS Type 1 is already helping the scientific community understand the causes of interstitial lung disease.



## What can you do to help?

After consulting with medical researchers and other rare disease organizations, the APS Type 1 Foundation has decided that the most effective way we can support researchers and clinicians to fight APS Type 1 is to offer research grants through the National Organization for Rare Diseases (NORD) and to establish a Canada-U.S. disease registry. Many other disease groups have started registries, which collect the basic data on all patients with a certain disease in order to assist health professionals diagnose, treat and hopefully cure the disease. Registries are particularly helpful for rare diseases as they group the information about existing patients. There are APS Type 1 registries in Europe, but no formal registries in North America. The combination of a registry and research grants will act as a catalyst for ground breaking research.

We need your help to raise the money to fund these projects, as well as to further education and awareness about this rare disease.

If you have any questions, please feel free to contact us at [info@apstype1.org](mailto:info@apstype1.org).