FOXP1 Syndrome

As of June 2023, two key online rare-disease databases, GARD and OrphaNet, will now specifically reference the clinician-recognized and modern term "FOXP1 Syndrome". Utilizing the consensus term "FOXP1 Syndrome" will now easily find information about FOXP1 syndrome, to understand what to expect as their family member develops and matures, and to find additional information and support. This is a major step forward as it enables practitioners to find online an official reference, information and resources on FOXP1 Syndrome.

Links:

- **Orphanet** https://www.orpha.net/consor/cgi-bin/OC_Exp.php?lng=EN...
  Orphanet is the portal for rare diseases and orphan drugs. Orphanet is a unique resource, gathering and improving knowledge on rare diseases so as to improve the diagnosis, care and treatment of patients with rare diseases. Orphanet aims to provide high-quality information on rare diseases, and ensure equal access to knowledge for all stakeholders. Orphanet also maintains the Orphanet rare disease nomenclature (ORPHAcode), essential in improving the visibility of rare diseases in health and research information systems.

  Orphanet was established in France by the INSERM (French National Institute for Health and Medical Research) in 1997.This initiative became a European endeavour from 2000, supported by grants from the European Commission: Orphanet has gradually grown to a Consortium of 40 countries, within Europe and across the globe.

- **GARD** https://rarediseases.info.nih.gov/.../intellectual...
  Genetic and Rare Diseases Information Center (GARD) is a United States public health resource that aims to support people living with a rare disease and their families with free access to reliable, easy to understand information, in English and Spanish. There is no advertising on their website, and GARD does not endorse or promote any companies, products, or services.

  GARD is managed by the National Center for Advancing Translational Sciences (NCATS), a part of the National Institutes of Health (NIH) and the US Federal government agency responsible for biomedical research. By advancing access to research information for rare diseases, GARD is using Translational Science to improve the research process to get more treatments to more people more quickly.