European pre-T1D Registry

WHO WE ARE?

European pre-T1D Registry is a network of investigators who register children and adults diagnosed with early-stage type 1 diabetes to inform about monitoring, trials, and treatment to delay or prevent disease progression. European pre-T1D Registry is operated by Helmholtz Munich under the umbrella of GPPAD & INNODIA. It was initiated in 2023 including data from more than 1000 persons.

WHO HAS EARLY-STAGE TYPE 1 DIABETES?

Diagnosis is made by testing for islet autoantibodies in a drop of blood in children and adults who have no known diabetes and no diabetes-specific symptoms. The presence of at least 2 islet autoantibodies indicates an early stage type 1 diabetes. This is an abnormality that is present months to years prior to clinical manifestation of type 1 diabetes. It indicates an immune response to the cells that produce insulin. By studying thousands of children with these antibodies, we can now predict who is most likely to progress to clinical disease within a relatively short time-frame. There is now a therapy that has been shown to delay progression.

OUR VISION

Early type 1 diabetes autoantibody screening programs are increasingly used within Europe with more and more individuals diagnosed with early-stage type 1 diabetes. It will be important to offer people with early stage type 1 diabetes information, clinical care and appropriate monitoring. For scientists, there is an opportunity to learn more about the disease and investigate how to prevent disease progression. Through the European pre-T1D Registry, we want to establish real-time monitoring, harmonized guidelines, and an information dissemination stream that will reduce type 1 diabetes severity, improve care and, through facilitating the execution of clinical trials, lead to type 1 diabetes prevention.

WHAT WE DO

A master database will be available to registered investigators into which pseudo-anonymised data from individuals diagnosed with early-stage type 1 diabetes can be transferred automatically and regularly. Data include autoantibody, metabolic and meta data identified through screening initiatives such as those of GPPAD, INNODIA, and Fr1da-Plex. Some financial reimbursement for data from future longitudinal monitoring and metabolic testing is available for sites not already financed by the existing programmes. Communication will be to site investigators and will include instructions and requirements for the automatic data transfer, patient information material, clinical trial information, and access to data for analysis. An open section for registered patients will be available in the future for direct access to clinical care and clinical trial material.

WHO CAN PARTICIPATE?

Site investigators who are involved in screening or identifying individuals with early-stage type 1 diabetes can register as a European pre-T1D Registry participant.

ALREADY REGISTERED ORGANIZATIONS INCLUDE:

GPPAD

Global Platform for the Prevention of Autoimmune Diabetes (GPPAD), which brings together several academic research institutions and hospitals in Europe to identify infants who have a genetic susceptibility for type 1 diabetes for participation in primary prevention trials where they are monitored for islet autoantibodies.

INNODIA

INNODIA, which has offered islet autoantibody screening to family members of patients with type 1 diabetes.

Fr1da

The Fr1da studies (Fr1da-plex) in Germany, which screen children in the general population for islet autoantibodies.

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