Primary Immunodeficiency in Kuwait NCT03618147 July 22, 2019

- **Study Title:** Kuwait National Primary Immunodeficiency Registry (KNPIDR)
- Estimated total study duration (months): 12
- **Background/Rationale**: Epidemiological data about PIDD in Kuwait is needed to better understand peculiarities and to compare them with other regions and ethnicity.
- **Study hypothesis:** PIDD is relatively common in Kuwait compared to populations from different geographic areas. The distribution of PIDD in Kuwait is different from other geographic areas with more severe forms being more frequent.
- **Brief inclusion and exclusion criteria of study participants:** PIDD patients presented at different clinics/hospital in Kuwait. Patients with secondary immunodeficiencies (drug induced, virus induced, and immunodeficiency associated with metabolic disorders... ect), will be excluded
- Estimated sample size of the study: All patients who were registered in KNPIDR since 2004 will be included in the study along with the new patients who will be recruited during the study period.
- Primary objectives:
 - Determine the prevalence and frequency of different PIDD in Kuwait
 - Identify clinical presentation patterns for PIDD in Kuwait
 - Identify natural history of PIDD in Kuwait
 - Help to asses epidemiology of PIDD in Kuwait
 - Determine particularities about PIDD affecting the population in Kuwait
 - Determine the health impact of PIDD in Kuwait
 - Development of strategies to improve the care and the quality of life of patients with PIDD
- Estimated total budget: \$50000

All PID patients diagnosed in Kuwait since 2004 were included. The patients were followed prospectively between January 2004 and December 2018 and their data was entered into a data form that is divided into 5 sections: sociodemographic data, diagnosis, clinical presentation, laboratory tests and treatment. The collected data was entered into a computerized database software program which was designed

The patients were diagnosed and classified according to the International Union of Immunological Societies, Primary Immunodeficiency Diseases Committee report on Inborn Errors of Immunity (2017). Secondary immunodeficiencies, were ruled out by obtaining detailed history and by performing appropriate testing when suspected. The immunological tests were performed included complete blood count with peripheral blood smear evaluation, serum immunoglobulins, antibody response to previous vaccines, lymphocyte phenotyping, and lymphocyte stimulation test. Autoantibodies testing, nitro blue tetrazolium dye test (NBT) or dihydrorhodamine (DHR) and complement hemolytic activity (CH50/100) with specific complement component were done when needed using the standard techniques. Genetic testing was done for most of the patients.