



# The Konya Declaration for Patients with Primary Immunodeficiencies

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## Introduction

Every year since 2004 when the J Project was launched, the growing interest and activity of devoted clinicians and scientists in Eastern and Central Europe (ECE) and elsewhere and their efforts to make a difference in the care of patients with primary immunodeficiencies (PIDs) in their regions and countries are clear [1]. A few Central European countries have now progressed to such an extent that they are approaching the professional standards of Western Europe in terms of diagnosis, clinical care, and education [2]. By contrast, in some countries, particularly in Central Asia, PID diagnostics and care are no further advanced than they were in Central Europe 30–40 years ago. There are also remarkable regional differences in patient management, particularly in large countries, such as Russia. One of the biggest challenges facing us now is providing differential assistance to achieve advances throughout the whole J Project area (Fig. 1), which currently has markedly different levels of complex PID care. Maybe we can take inspiration from the Turkish dervishes. During their unique dancing performance, they hold one of their extended arms with the palm up, suggesting receiving, and the other arm with the palm facing downwards, suggesting giving. We must continually encourage those centers

and groups with advanced levels of PID care to share their knowledge with those most in need of it.

Fifteen years have passed since we embarked on the exciting professional journey that is the J Project [1–7]. Every year has been demanding, but in different ways, with the continual addition of new centers and countries. The 237 physician education meetings till December 2019, the J Project congresses organized in Turkey, and the Antalya Declaration issued in 2014 have greatly contributed to our joint success. Major reasons to revise the Antalya declaration included that revision was scheduled for 2020 when it was issued and several changes in the field of PIDs, like the number of diseases, more widely use of next generation technology and newborn screening, and more JP member countries and more SC members who wanted to be part of a new JP Declaration. The Konya Declaration endeavoring to express the conceptual framework, the vision, and mission of the J Project is admittedly more demanding and critical. The challenges surrounding the rapidly growing field of PIDs must be met all over the world by health care providers and call for urgent and decisive actions. We believe that the better management of PIDs can help us to understand immunology and human diseases better and to serve patients with more humility. The past 15 years provided an excellent opportunity to build up a professional community in many countries in Eastern and Central Europe and elsewhere in order to provide a better care of patient with PIDs. Devoted PID working groups were established and developed, and remarkable number of new patients were diagnosed and started on treatment. Among great successes should be mentioned the international meetings called J Project Congresses and the establishment of a growing collaboration with other international societies especially the ESID. The unequal distribution of knowledge in different countries

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