

## The 10<sup>th</sup> anniversary of the world primary immunodeficiency week: A J Project celebration

Professional celebrations are unique as they represent long-term completion of purposeful work, togetherness, and public spirit. The starting point is always challenging as the establishment of a joint program should be both vaticinal and inciting. The establishment of such a tradition usually follows the birth of a discipline for many decades. Immunology had been a well-established clinical and research discipline when the European Federation of Immunological Societies (EFIS) brought to life the *Day of Immunology* (DoI) to increase public awareness of this important branch of learning, on April 29, 2005 (<https://www.dayofimmunology.org>).

Soon after this, the *World Primary Immunodeficiency Week* (WPIW) was established and dedicated to increasing global awareness on primary immunodeficiency disorders (PIDs) or inborn errors of immunity each year, on April 22–29, 2011 [1]. The ambition of the PID professional community to dedicate a week instead of a day could well be attributed to the underdevelopment of PID diagnostics and patient care compared to the other major fields of clinical immunology, allergy, and autoimmunity. These annual events are necessarily supplemented with even more challenging educational programs.

### The J Project

At the turn of the millennium, it was realized that PIDs were remarkably underdiagnosed and in most of the Eastern- and Central European countries, the number of registered patients was less than 10 [2]. These dramatic statistics presented by the European Society for Immunodeficiencies (ESID) brought into action the ambitious physician education and clinical research collaboration program referred to as the

J Project (JP) [2]. Launched in 2004, the project started to spread first in Central Europe, and from 2007 in Eastern Europe, resulting in a year-by-year increase of diagnosed and treated PID patients [3]. The key events of the Project have been educational meetings not only for physicians but also for other health care professionals, patients and families, in addition to establishing national and regional registries and working groups and starting joint clinical research [4]. The Project has been spreading to the east and reaching countries like those in Central Asia, and JP meetings are now extended to Russian Far East, Iran, and Turkey [5, 6]. By 2020 the Project has grown into a community of 32 countries and the number of JP meetings has reached an average of 3.6 per month (Figs. 1 and 2). JP meetings are organized all over the year, but April is a prominent month.

### The 10<sup>th</sup> anniversary of the WPIW

April has always seen a higher number of JP Meetings attributable to the DoI and the WPIW. Still, the record number of 16 meetings this year is outstanding and unique. Although it was spontaneous, it would be hard not to attribute it to the 10<sup>th</sup> anniversary of the WPIW. This has been a silent celebration by the J Project community showing sensitively how traditions like the DoI and the WPIW may change our professional life and contribute to the progress of our wonderful discipline. Table 1 shows the list of 16 JP meetings and our “April heroes” organizing these events and celebrating the 10<sup>th</sup> WPIW in a fully professional way, on behalf of the whole JP community. The subjects discussed at the meetings varied from general diagnostics and treatment of patients, infectious

and non-infectious manifestations of PID, through immunization practices, education of parents, students, and school teachers to recent understanding of the disease-related risks of COVID-19 in PID patients [7]. We have also reached the 300<sup>th</sup> JP meeting in this grandiose month and welcomed Montenegro, the youngest member country (Table 1).

### Unexpected challenges in 2020

The J Project has always been changing ever since its creation in 2004, recognizing the increasing need for public and physician education in Central Europe, and then in Eastern Europe, and subsequently elsewhere, most recently in Central Asia and Far-East Russia [6]. This evolution, based on the recognition of professional needs has resulted in changes and rearrangements of the JP program throughout Eurasia. The prime focus of the collaboration has recently been shifted from clinical education to genetics education, thanks to the tremendous developments that have occurred in the field of PIDs. In 2019, we expressed our enthusiasm concerning the success of how the knowledge of next-generation sequencing technologies had been disseminated, making it possible to define the genetic basis of more PIDs [5, 7]. However, in 2020 events took an unexpected turn, forcing the world to face new challenges. The very existence of humanity has been threatened by a viral disease caused by severe acute respiratory syndrome coronavirus (SARS-CoV-2) [8]. Most research laboratories, centers, and institutions have changed direction and focused their research on studies of the mechanisms, prevention, and treatment of COVID-19 [9]. The JP has joined forces with the Casanova Lab at the Rockefeller



Figure 1. The geographic extension of the J Project in 2020.

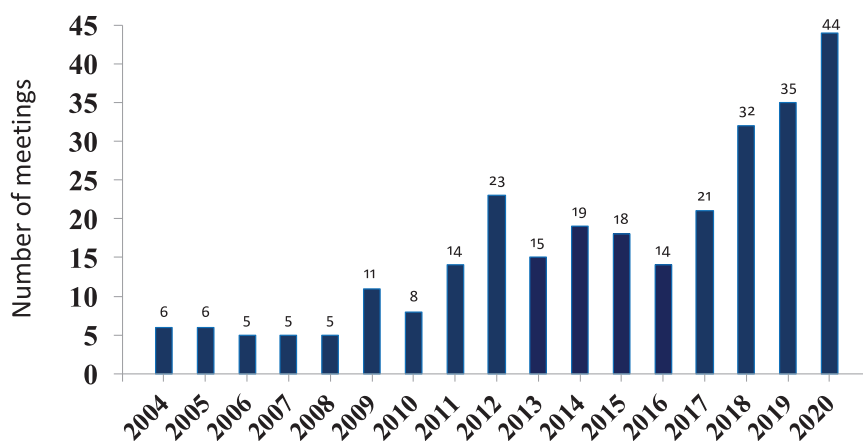


Figure 2. The yearly number of J Project meetings between 2004 and 2020.

University and Paris, which is involved in PID research and running the COVID-19 Human Genetic Effort, an international project spanning over 50 sequencing hubs around the world. We have decided to extend participation in the COVID-19 research and the JP is now playing an important role in this research by establishing participating centers all over Eurasia and increasing awareness of unusual COVID-19 cases at JP meetings (Table 1). It will contribute to the research of monogenic causes of COVID-19 and resistance to SARS-CoV-2 infection. We hope that this research will help to slow the coronavirus pandemic and, eventually, eradicate the disease, so that we are able to focus once again on long-term diseases, such as PIDs.

### Collaboration and research

It is hard to express the wonderful feeling throughout the year about the commitment of many colleagues in Eurasia to the shared mission of the JP in 2020, under unusually difficult circumstances. Most colleagues realized that in difficult times, we should be even stronger to carry on with our responsibility. Extending the scope of the traditional PID education program to PID-COVID-19 gave a unique strength to the JP and resulted in a new dynamic by organizing another record number of meetings (Fig. 2). The invitation of speakers to present cutting-edge research at several JP meetings gave a new aspect of our program. Pertinent

to this, the discovery of type 1 interferon deficiency in severe COVID-19 was recently selected by Nature as one of the 10 most remarkable discoveries from 2020 across all fields of science [10, 11]. The first authors of these two publications presented their research at several JP meetings last year.

We also took a remarkable step forward last year to a closer collaboration with ESID. This was achieved by the participation of ESID leaders as speakers at JP Meetings, and by the financial support of a number of meetings by ESID in addition to the Jeffrey Modell Foundation and other sponsors. The J Daughter Central Asia project reached new milestones by joining Uzbekistan and Kyrgyzstan [5, 6]. This year was also very successful in terms of publishing joint papers: one article on the Konya Declaration, one on the achievements of the J Siberia Project, both published in the PID-focused *J Clin Immunol*, as well as a remarkable set of 11 research articles in *Front Immunol*, from the Eastern and Central European J Project area [7].

These remarkable successes could only be achieved by the close collaboration of an orderly network with a shared vision and responsibility. It is timely to summarize various parameters of PID diagnosis and treatment in a comprehensive review showing the outcomes of the JP and companion programs to improve the complex patient care in the 32 countries. While we have been resilient and

**Table 1.** Sixteen J Project meetings in April, 2021 (N° 286–301)\*

City, Country	Organizer(s)	Date	Subject
South-East Anatolia, Turkey (286)	Ismail Reisli	April 6	PID and infections
Warsaw, Poland (287)	Malgorzata Pac, Ewa Bernatowska	April 10	Immunization in PID patients
Debrecen, Hungary (288)	Noémi Miltner, László Maródi	April 17	PID for students and teachers
Kyiv, Ukraine (289)	Alla Volokha	April 22-23	PID and rheumatologic diseases
Timisoara, Romania (290)	Mihaela Bataneant	April 22-23	PID – general features
Plovdiv-Sofia, Bulgaria (291)	Mariana Murdjeva, Elissaveta Naumova	April 22-29	PID and COVID-19
Budapest, Hungary (292)	Katalin Haraszti, László Maródi	April 23	PID for children and parents
Riga, Latvia (293)	Natalja Kurjane	April 24	PID care in Latvia-Lithuania
Tehran, Iran (294)	Nima Rezaei	April 26-29	PID and COVID-19
Baku, Azerbaijan (295)	Gulnara Nasrullayeva	April 28	PID and COVID-19
Bratislava, Slovakia (296)	Peter Ciznar	April 28	PID diagnostics and treatment
St. Petersburg, Russia (297)	Marina Guseva	April 29	PID and COVID-19
Yerevan, Armenia (298)	Sevan Iritsyan	April 29	PID and COVID-19
Podgorica, Montenegro (299)	Lidija Pocek	April 29	PID – joining the J Project
Minsk, Belarus (300)	Mikhail Belevtsev	April 29-30	6 <sup>th</sup> International PID - J Project Meeting
Osh city, Kyrgyzstan (301)	Bubusaira Orozbekova Irina Tuzankina	April 29-30	PID – general features

\* Numbers in brackets indicate the global number of meetings since the beginning of the J Project on March 12, 2004 in Targu Mures, Romania; PID, primary immunodeficiencies; COVID, coronavirus infectious

productive, we encourage our members to increase efforts to remain connected to each other, keep open doors to new regions and countries, and strengthen the connection with partner organizations and immunological societies like the EFIS and the ESID.

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