



# THE J PROJECT

2015



# THE J PROJECT

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March, 2016

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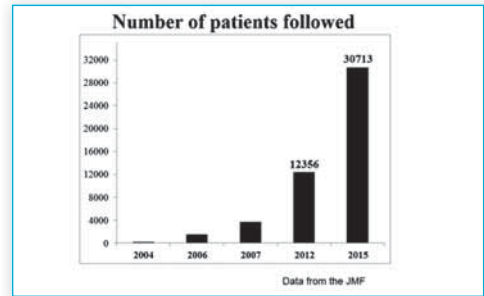
The last decades have seen unprecedented increase in our understanding of immunological and genetic basis of primary immunodeficiency diseases (PIDs). The number of known PID genes has reached 300 and considering the varying phenotypic expression of gene defects predisposing to PID the number of clinical phenotypes are much higher. Much has been accomplished in Eastern and Central Europe (ECE) under the program called The J PROJECT aiming to increase awareness of PIDs and to improve medical care and training in this domain.

During the year of 2014 eighteen J Project Meetings were organized in 12 member countries and we had the same number of meetings in 2015 suggesting that we maintained the increased level of awareness activity. In the first five years of the J PROJECT (2004–2008) the number of meetings were 5 or 6 per year and it increased to more than ten in 2009, a remarkable year in the history of the J PROJECT for a couple of other reasons as well. Then, from 2012 the number of meetings remained above 15 per year with a record number of 23 per year in this 2012. The number of meetings scheduled for 2016 is also 23 and if we will successfully have organized these programs a total number of J Project meetings will exceed 150 (Figure 1). The number of patients followed because of proven or suspected PIDs has increased in parallel with these physician education meetings and reached 12 356 by 2012 and 30 713 by 2015 (Figure 2; data from the Jeffrey Modell foundation). These data suggested further that awareness activity is indispensable to call proper attention to PIDs.

Figure 1



Figure 2



In 2015 we successfully continued the J2 Project established in 2013 and aimed at training medical professionals in PID gene analysis assays. In particular, 6 colleagues from Russia (3), Romania (1), Turkey (1), and India (1) received a one month intensive training in targeted gene sequencing at the Genetics Lab of the Debrecen Jeffrey Modell Diagnostic and Research Center. This program was damaged by the brutal closing of our Department in November, 2015.

Despite these successes, however, much remains to be done to achieve the goals outlined twelve years ago (see J Project Booklet 2004). To further define and confirm the original goals we have approved last year the Antalya Declaration which calls for prompt and effective action by governments to ensure the application of current knowledge to the diagnosis and treatment of PID patients. The following five objec-

tives are targeted for attainment by the end of 2020: 1) Education of medical students and healthcare professionals and continuing medical education of physicians practicing in primary care settings and hospitals; 2) Public awareness should be raised to publicize that most PID patients remain undiagnosed and untreated; 3) PID genetic diagnostics should be managed free of charge in each of the J Project countries; 4) PID registry should be established in every J Project country; 5) Personalized immunoglobulin replacement and hematopoietic stem cell transplantation should be made available to PID patients in each J Project country. All the points outlined above should result in measurable reduction of co-morbidity and mortality of PID patients. They should also result in the lag between the first manifestation and definitive diagnosis of PID. These mission statements are also listed in the new J Project website (*Figure 3*; <http://jprojectnetwork.org>).

László Maródi

Figure 3



*PRO COOPERATIONE award to professor Ewa Bernatowska for her outstanding contribution to the success of the J Project collaborative research*

## Meetings in 2015

City ( <i>Country</i> )	Date
1. Moscow ( <i>Russia</i> )	February 18–19
2. Budapest ( <i>Hungary</i> ) – JPSC	March 5–6
3. Bratislava ( <i>Slovakia</i> )	April 21–22
4. Minsk ( <i>Belarus</i> )	April 23–24
5. Debrecen ( <i>Hungary</i> )	April 25–26
6. Tehran ( <i>Iran</i> )	April 28–29
7. Antalya ( <i>Turkey</i> )	April 29
8. Orel ( <i>Russia</i> )	May 14–15
9. Sakarya ( <i>Turkey</i> )	May 17
10. Zhytomyr ( <i>Ukraine</i> )	May 21–22
11. Ljubljana ( <i>Slovenia</i> )	May 22–23
12. St. Petersburg ( <i>Russia</i> )	June 3–4
13. Perm ( <i>Russia</i> )	July 2–3
14. Timisoara ( <i>Romania</i> )	September 3–4
15. Tehran ( <i>Iran</i> )	October 8–9
16. Bořetice ( <i>Czech Republic</i> )	November 19–20
17. Plovdiv ( <i>Bulgaria</i> )	November 20
18. Tirana ( <i>Albania</i> )	November 20–21

**Hosts:** Irina Kondratenko (*ikondratenko@rambler.ru*)  
**Venue:** Moscow City Hall  
**Main topic:** International education program J Project: “Primary immunodeficiencies. The right to life”

### PROGRAM

Success of treatment depends on the correct diagnosis.

*I. Kondratenko (Moscow)*

Common variable immunodeficiency – diagnosis of exclusion.

*E.A. Latysheva (Moscow)*

Approaches to the treatment of patients with primary immunodeficiencies.

*T. Latysheva (Moscow)*

The J-project meeting in Moscow took place on February 19, 2015. The meeting organized jointly by Biotest pharma, Prof. Tatiana Latysheva, Prof. Irina Kondratenko. The event was attended by about 70 participants from all Russian regions (Moscow and Moscow region, Tula, Ekaterinburg, Chelyabinsk, Ulan-Ude (Buryatia), Kasan (Tatarstan), and many other towns. After lectures we had very good dialog and discussion with our colleagues (Diagnostic and legalistic questions were discussed), as I can remember in a year after the conference.

*I. Kondratenko*



*Doctors from various regions of Russia who attended the J Project meeting*



*Lecture on diagnostics and treatment of primary immunodeficiency by I. Kondratenko*

*Culture program and dinner.  
L→R: T. Latysheva,  
I. Kondratenko and their  
colleagues  
from other Hospitals.*





**Hosts:** László Maródi (*edamarodi@gmail.com*)**Venue:** Grand Hotel Margitsziget

## SUMMARY

The J Project Steering Committee Meeting was held at the Grand Hotel Margitsziget on March 6, 2015, Budapest, Hungary. Strategic topics discussed during the Meeting were as follows:

- 1) Progress report by SC members with special focus on the Antalya Declaration
- 2) Ongoing scientific projects (CGD, NBS, WHIM)
- 3) New project (immunology and genetics of HIES in J Project countries)
- 4) Regular SC Meetings and J Project Congresses
- 5) J Project Registry
- 6) J Project website

As a Welcome speech László Maródi presented on Global J Project activity in 2014. Progress reports with special focus on national achievements were presented by each center leader. Ongoing research on chronic granulomatous disease patients coordinated by Tadej Avcin was presented by Gasper Markelj. Achievements on studying Nijmegen-breakage syndrome was summarized by Ewa Bernatowska. Another running clinical research project on warts-hypogammaglobulinemia-infection-myelokathexis was summarized by Kristina Mironska. Future collaborative research projects including a cohort study on STAT3 mutations and epidemiology and immunology of hyper-IgM syndrome in J Project countries were also suggested. Updates were on SC Member list, J Project Meetings 2015, the need to establish the J Project Juniors' Group and their own Meeting, biennial SC Meetings and the 2nd J Project Congress in Antalya, Turkey on March 1-4, 2016. Discussions were made on J Project Center of Excellence award (for centers) and Pro J Project award (for persons). Further discussions were made on organization and running the J Project Registry and J Project website.

*László Maródi*

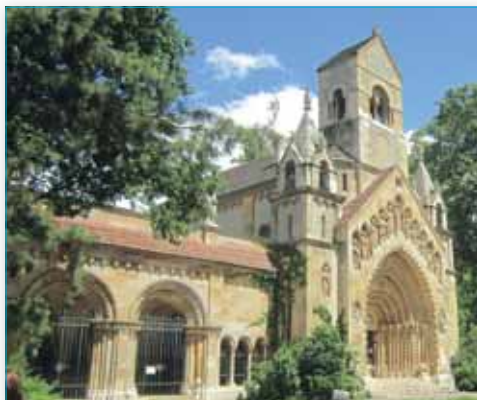


*L→R: A. Sediva, E. Bernatowska, L. Maródi, M. Serban, I. Tuzankina*



*Participants of the 2015 J Project Steering Committee Meeting*





*Premontre Konvent Church and park view at Margitsziget*



*Delegates of the SC Meeting.*

*L→R: N. Kristan (Slovenia), A. Volokha (Ukraine), S. Deryabina (Russia),  
A. Šediva (Czech Republic), M. Guseva (Russia), L. Vegh-Libai (Slovakia),  
V. Selmanovic (Bosnia & Hercegovina), T. Prokofjeva (Latvia), S. Velbri (Estonia),  
I. Tuzankina (Russia), I. Savchak (Ukraine), L. Chernyshova (Ukraine), A. Elmarsafy (Egypt),  
F. Peissker (Germany), L. Maródi (Hungary), M. Bataneant (Rumania), M. Belevtsev (Belarus),  
A. Bondarenko (Ukraine), M. Serban (Rumania), G. Markelj (Slovenia),  
E. Bernatowska (Poland), E. Thomas (Germany), M. Pac (Poland), K. Vámos (Hungary),  
E. Naumova (Bulgaria), M. Becker (Germany), N. Otarbayev (Kazakhstan),  
H. Abolhassani (Iran), I. Reisli (Turkey)*

**Hosts:** Peter Čižnár (*ciznar@dfnsp.sk*)**Venue:** Hotel Austria Trend**PROGRAM****April 22**

Introduction and overview of primary immunodeficiencies

*Čižnár P. (Bratislava)*

T cell deficiencies in childhood

*Förster-Waldl E. (Viedeň)*

Dominant negative STAT3 mutation in hyper-IgE syndrome

*Pistár Z., Soltész B., Maszárovics Z., Sarkadi A. K., Maródi L., Tóth B. (Debrecín)*

Impaired development of IL-17-mediated immunity in a patient with a novel STAT1 mutation

*Soltész B., Tóth B., Csorba G., Taskó S., Sarkadi A. K., Maródi L. (Debrecín)*

A new autoinflammatory syndrome with recurrent fever, severe anemia and B lymphocyte immunodeficiency

*Kayserová J. (Praha)*

Diagnostic approach in PID

*Thon V. (Brno)*

Hereditary angioedema

*Jeseňák M., Bánovčín P. (Martin)*

Diagnostic and therapeutic approach in chronic enteropathy in patients with CVID – Case report

*Raffáč Š. (Košice)*

First cases of Familial Mediterranean Fever in Slovakia

*Dallos T., Lukáčiková Gálová L., Mačejková E., Ilenčíková D., Kovács L. (Bratislava, Nitra, Banská Bystrica)*

Hypogammaglobulinemia in childhood

*Šedivá A. (Praha)*

CVID – Case presentation

*Straková J. (Martin)*

Selective deficiency of IgM

*Chovancová Z. (Brno)*

Antiinfective strategy in immunodeficient patients

*Demitrovičová A. (Bratislava)*

Rapid-push method – clinical experiences

*Čižnár P., Smutková M. (Bratislava)*

From our daily clinical immunology praxis – short communications

*Hrubíško M., Kayserová H., Kossarová K., Horáková J., Brezina M., Pružinec P. (Bratislava)*

Conclusion remarks

Social event

*Peter Čižnár*



**Hosts:** Mikhail Belevtsev (*belevtsev\_m@mail.ru*)

**Venue:** Hotel Belarus

## PROGRAM

### Plenary session 1

Immunodysregulation in PID\_part 1  
(*lymphoproliferation, autoimmunity*)

Moderators: NimaRezaei, MD, PhD,  
Anne Durandy, MD, PhD

10.35–11.05 Constitutively activated  
PI3K signaling – a novel cause of class  
switch recombination deficiency

Anne Durandy, MD, PhD, France,  
Paris

INSERM UMR 1163, Imagine Insti-  
tute; Department of Immunology and  
Hematology, Hôpital Necker Enfants  
Malades

11.05–11.20 Clinical case of combined  
immunodeficiency due to PIK3R1  
mutation

Elena Vlasova, MD, PhD, Russia,  
Yekaterinburg

Ural Federal University named after  
the first President of Russia B.N. Yelt-  
sin

11.20–11.35 Activated phosphoinositide  
3-kinase  $\delta$ -syndrome. Analysis of 7  
cases

Inga S. Sakovich, S. Sharapova, PhD,  
Belarus, Minsk

Belarusian Center for Pediatric Oncol-  
ogy, Hematology and Immunology

11.35–12.00 Autoimmune disease in chil-  
dren with primary immunodeficien-  
cies

Irina N. Smirnova, MD, Russia, Mos-  
cow

Federal Scientific and Clinical Centre  
of Pediatric Hematology, Oncology  
and Immunology named after Dmitry  
Rogachev

11.45–12.00 Immunological and genetic  
diagnostics of chronic lymphoprolif-  
eration in children

Svetlana Sharapova, PhD, Belarus,  
Minsk

Belarusian Center for Pediatric Oncol-  
ogy, Hematology and Immunology

12.00–12.30 coffee pause

### Plenary session 2

Immunodysregulation in PID\_part 2  
(*bowel diseases and neurological  
problems*) and PID Registries

Moderators: Anastasia V. Bondaren-  
ko, MD, PhD, Svetlana Sharapova,  
PhD

12.30–12.45 Inflammatory bowel disease  
– is it primary defect of innate immu-  
nity?

Natalia Kalinina, MD, PhD, profes-  
sor, Russia, St-Petersburg

All-Russian Center of Emergency and  
Radiation Medicine of A. Nikiforov  
Russian Emergency Situations Minis-  
try

12.45–13.20 Homozygous mucosa-asso-  
ciated lymphoid tissue (MALT1) mu-  
tation in two siblings with immunode-  
ficiency and chronic enteropathy

Gasper Markelj, MD, PhD, Slovenia,  
Ljubljana

Department of Allergology, Rheuma-  
tology and Clinical Immunology Uni-  
versity Medical Centre Ljubljana

13.20–13.35 Brain immunology

Viktorija Kenina MD, PhD, Latvia,  
Riga

University Medical Hospital named after Stradynia

- 12.30–12.45 Brain injury and immunological manifestation in patient with combined immunodeficiency

*Anastasia V. Bondarenko, MD, PhD, Ukraine, Kiev*

Medical Academy for Postgraduate Education

- 12.45–13.00 Neurological disorder in patient with CVID (Clinical case)

*Kyrjane Natalia, MD, PhD, Latvia, Riga*

University Medical Hospital named after Stradynia

- 13.00–13.35 National registry of PID in Czech Republic. Data of 775 patients

*Tomáš Milota, MD, The Czech Republic, Prague*

2nd Faculty of Medicine and University Hospital in Motol

- 13.35–13.50 National registry of PID in Belarus. Data of 300 patients

*Svetlana Aleshkevich, MD, Belarus, Minsk*

Belarusian Center for Pediatric Oncology, Hematology and Immunology

- 14.00–15.00 Lunch

### Plenary session 3

New technologies in PID diagnostics and Hereditary Angiodema

Moderators: *Gasper Markelj, MD, PhD, Michael Belevtsev, PhD*

- 15.00–15.40 Application of NGS technology for HLA-typing high resolution in HSCT

*Florian Alois Graedler, PhD, Nikolay Egorov Germany, Munich*

Illumina GmbH Zeppelinstr

- 15.40–16.20 Hereditary Angioedema: A Medical/Scientific Overview. Symptomatology, diagnosis, pathogenesis, treatments, and ongoing research/scientific interest

*Dr. Bruce Zuraw, Professor of Medicine, USA, San Diego*

The Division Chief of the Division of Rheumatology, Allergy and Immunology in the Department of Medicine

### Plenary session 4

Treatment of PID

Moderators: *Gasper Markelj, MD, PhD, Michael Belevtsev, PhD*

- 16.20–16.35 Rituximab influence on the treatment and diagnostic results of primary immunodeficiencies

*Anastasia S. Pilipchik, MD, S. Sharapova, PhD, Belarus, Minsk*

Belarusian Center for Pediatric Oncology, Hematology and Immunology

- 16.35–16.55 Treatment with Sirolimus (RAPAMICIN) of patients with primary immunodeficiency

*Elena V. Deripapa, MD, Russia, Moscow*

Federal Scientific and Clinical Centre of Pediatric Hematology, Oncology and Immunology named after Dmitry Rogachev

- 16.55–17.25 Hematopoietic stem cells transplantation for treatment primary immunodeficiencies in Belarus (18 patients experience)

*Olga V. Aleinikova, MD, PhD, professor, Belarus, Minsk*

Belarusian Center for Pediatric Oncology, Hematology and Immunology

- 17.25–18.00 Closing ceremony





## SUMMARY

The 4th International Conference of Primary Immune Deficiencies has been organized within the limits of J Project on of April 22th – 25th, 2015 in Minsk (Belarus). More than 200 pediatricians and immunologists from Belarus and 12 counters participated in the conference. The leading PID experts Anne Durandy (France), Nima Rezaei (Iran), Gasper Markelj (Slovenia), Tomáš Milota (The Czech Republic), Bruce Zuraw (USA), Kyrjane Natalia (Latvia), Natalia Kalinina, Irina Tsuzankina (Russia) have given reports. Specialists from Belarussian Research Centers of Pediatric Oncology, Hematology and Immunology reported about Natinonal PID Registry (Belevtsev M., Aleshkevich S.), new form of PID such as APDS (Sharapova S.) and results of transplantation PID patients (Aleinikova O.).

*M. Belevtsev and S. Sharapova*



*L→R: N. Rezaei and O. Aleinikova*



*M. Guseva, A. Semenov, A. Bondarenko, S. Sharapova*



*O. Aleinikova opening the Conference*



*L→R, O. Rabosh, A. Bondarenko, T. Prokofjeva, L. Chernyshova*



*M. Belevtsev (L) and S. Sharapova (R) presenting their talks*

**Host:** László Maródi ([eramarodi@gmail.com](mailto:eramarodi@gmail.com))

**Venue:** University of Debrecen, Kátai Gábor Hospital, Gróf Tisza István Hospital

## World Primary Immunodeficiency Week

### Organized jointly by the

*Departments of Infectious and Pediatric Immunology and Immunology,*

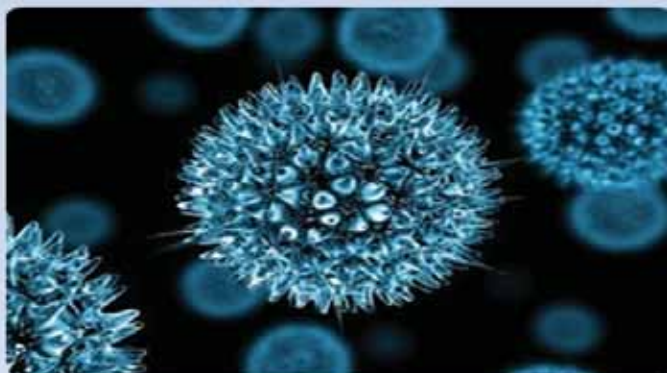
*Faculty of Medicine, University of Debrecen,*

*Hungarian Society for Immunodeficiencies (HUSID),*

*Hungarian Patients' Group for Immunodeficiencies (HUPID),*

*Foundation for Children with Immunodeficiencies (FCI),*

*The DEBRECEN HEROs*



# PROGRAM

**April 22**

## **Early recognition of PIDs in childhood**

**Venue:** Kindergarten, Clinical Center, University of Debrecen  
**Local organizer:** Kovácsné Ibolya Hajzer, Head of Kindergarten  
**Subject:** **PIDs presenting in infants and preschool children**  
**Speaker:** Adrien Katalin Sarkadi  
**Target Groups:** Day nursery and kindergarten attendants

**April 23**

## **Primary immunodeficiency phenotypes**

**Venue:** Kátai Gábor County Hospital, Karcag  
**Local organizer:** Judit Oszlács consultant infectologist and quality control group leader  
**Subject:** **Epidemiology, recognition and treatment of PIDs**  
**Speaker:** László Maródi  
**Target groups:** Hospital doctors, general practitioners, nurses

**April 24**

## **Open day**

**Venue:** **Molecular Immunology and Genetics Laboratory,  
Dept. of Infectious and Pediatric Immunology**  
**Local organizer:** Lajszné Beáta Tóth  
**Subject:** **Immunological and genetic diagnostics of PIDs**  
**Speakers:** Lajszné Beáta Tóth, Beáta Soltész, Szilvia Taskó, Gabi Csorba  
**Target groups:** Grammar school students, medical students, residents, specialists

**April 25**

## **HUSID – HUPID J Project Conference**

**Venue:** **Lecture Room, Dept. of Infectious and Pediatric Immunology**  
**Local organizer:** Tóthné Mónika Apáti Nagy, László Maródi  
**Subject:** **Molecular genetic analysis of PIDs**  
**Speakers:** Lajszné Beáta Tóth, Beáta Soltész, László Maródi  
**Target groups:** Patients with PID and their relatives, immunology specialists, geneticists, laboratory medicine professionals  
**Surprise introduction and show by the DEBRECEN HEROs:**  
Child tales, flute and guitar concert and singing, drawing and coloration, pearl tackling, decoration, glimmering tetoo, nail polishing, rope and hair making.



**April 27**

**Clinical diagnosis of PIDs in community hospitals**

**Venue:** Gróf Tisza István Hospital, Berettyóújfalú  
**Local organizer:** László Pete, medical director  
**Subject:** **Differential diagnostics and treatment of PIDs**  
**Speaker:** László Maródi  
**Target groups:** Hospital doctors, general practitioners, nurses

**April 28**

**PID warning signs**

**Venue:** FÓRUM Shopping Center, Debrecen  
**Local organizer:** Ajtony Átányi, general manager  
**Subject:** **Common signs and symptoms of PIDs**  
**Speakers:** Baranyáné Rozáli Kiss, Göncziné Mónika Révész, Szilvia Taskó, Gabi Csorba  
**Target groups:** Employees and customers of FÓRUM Shopping Center

**April 29**

**World Day of Immunology**

**Venue:** Lecture room, Debrecen Committee of the Hungarian Academy of Sciences  
**Local organizer:** Tamás Bíró  
**Subject:** **Immunology in plain language**  
**Speakers:** Sándor Sipka: Kesztyüs Loránd memorial lecture  
Éva Rajnavölgyi: Race against and living with viruses  
Andrea Szegedi: Itching and allergy  
Zoltán Szekanez: Life expectancy of patients with rheumatic diseases  
Adrien Katalin Sarkadi: Inherited primary immunodeficiencies  
Tamás Bíró: Avoid drugs, rather grease and oil yourself with them  
**Target group:** Grammar school students

## SUMMARY

The World Primary Immunodeficiency Week (WPIW) is an uplifting period for immunologists, as it provides endless opportunities to talk about PIDs in various communities, and to communicate knowledge about clinical diseases, disease manifestations and new treatment options for patients. This week also allows PID activists to raise awareness among children in nurseries, and students in elementary schools, high schools, and medical schools, to implement targeted interactions and to talk to professionals and nurses in institutions and family settings. The Debrecen PID group has adopted a number of unique approaches this year, including visits to nurseries, and community hospitals, and interventions targeting grammar school students, and

workplaces, including FORUM, the largest shopping center in town, with 1000 employers and 25 000 visitors daily. We were delighted to play host to the Debrecen Heroes, a group of enthusiastic young people that organizes programs to help disabled individuals and other communities in need. The Heroes also award a Challenge Cup to civil groups or institutions, in appreciation of their outstanding efforts in their field. This year the Cup was awarded to the Department of Infectious and Pediatric Immunology.

### **The Debrecen Hero's group support PID patient care**

On March 20, 2015, the Debrecen Heros group organized a charity concert, the proceeds of which were offered to the Department of Infectious and Pediatric Immunology, to support the care of PID patients. The group also joined forces with the Foundation for Children with Immunodeficiencies (FCI) and the Hungarian Patients' Group for Immunodeficiencies (HUPID), to organize and participate in the WPIW program. They decided to spend a whole day at the Department, together with patients, parents and doctors. After the donation, dozens of toys and the Challenge Cup were presented to Dr Maródi, and there was a flute recital and the reading of a poem written for the Heros by Ervin Aranyosi, specifically for this event (see back cover). During the meeting of parents and doctors, the Heros organized a wonderful program for the children, full of joy and happiness, with lots of surprises. This created a unique atmosphere, enabling the children to forget their problems and become just children again for a while. The program ended with the release of balloons sent to Debrecen by the Jeffrey Modell Foundation. Based on this very positive experience, the Heros decided to stay in touch with the PID group and the FCI in the future, for the benefit of sick children.

*László Maródi and Noémi Miltner*



*Zsuzsanna Vincze*



*N. Miltner holding the FCI T-shirt*



*On behalf of the Debrecen Heros, Csilla Demeter gives over the Challenge Cup and many presents*



*UL: Children in the rumpus room; UR: P. Nagy and two of his children, Lili and Milan;  
LL: K. Csorba showing his origami bird; LR: K. Csorba, Lili Nagy and A. Mázló-Türk*





*Balloon realase on campus; UL: L. Maródi and G. Maródi; UR: G. Kürti, P. Nagy and R. Nagy; LL and LR: Balloon realase in front of the Dept. of Infectious and Pediatric Immology*



*Meeting of parents and doctors*

**Hosts:** Nima Rezaei ([rezaei\\_nima@yahoo.com](mailto:rezaei_nima@yahoo.com))

**Venue:** Health and Art (HEART) Group, Research Center for Immunodeficiencies Avicenna Hall, Tehran University of Medical Sciences

## PROGRAM

The voluntary group “Health and Art” started working officially on April 28th, 2015 at the same time with “World Immunodeficiency Week”.

This group as a part of Universal Scientific Education and Research Network (USERN) used advantages of artists’ creativities and abilities along with doctors and health personnel, aims to provide a situation in which they can release anxiety and worry of sick children and their families in order to make hopelessness less important in their minds since they won’t have it anymore.



*Health and Art (HEART) Festival at the Avicenna Hall*

In that ceremony, they performed songs and showed artists’ works, etc. At the end of the ceremony, a memorandum of understanding was signed between the heads of School of Medicine, Tehran University of Medical Sciences and the School of Fine Arts, University of Tehran to support “Psychological Health of Sick Kids”.

“Help the Health with Art, to Give a Smile to a Beating HEART”

According to the public relations department of “Health and Art”, Doctor Nima Rezaei, who is the founder of the HEART and was in charge of holding the special program for commemorating the World Immunodeficiency Week, emphasized on the importance of art in curing sick people. He said “It’s not enough that doctors only recognize the illness of sick people; hence we all need to do something important to have influence on sick people and their life to improve the way they are living in order to help them cure. He added “the experience of being with sick children and their families shows that when they’re not hopeless and they are hopeful for curing, the process of curing will pass fast in a better way, so they just need to be hopeful and full of positive feelings.” He also mentioned that borders should not be obstacles for science developments said; sometimes there are many obstacles, boundaries and limits for many doctors in medical fields, but there are not only doctors who can help sick people to be cured, and in many cases artists can use their works and art to help them

cure. He said “When sick children are in the period of curing their souls need help as their bodies, we need artists to do so in this case.”

So, the Health and Art (HEART) group formally started its activity as a volunteer group, consists of a number of medical doctors with interest on Art, and a number of artists with interest of Health, who focused their social activities on mental health of pediatric patients. The HEART members are doing their best to help sick children to be strong for treatment, to be hopeful and happy as these are the keys to a good treatment. The HEART group is an international network, which all members are trying to help ill children and try to make them happy and hopeful by their presence in health care centers. They have already organized several activities, which are welcomed by the physicians, artists and patients.

The aims of the HEART are as follow: – Providing the art platform to provide better health care, – Providing the context of art to provide better health services in the community, – Informing members of health care centers about the impact and effect of art on health, – Providing chances for sick people to use their body language, and rely on non-verbal communication to express their feelings, – Controlling emotions, reducing anxiety and reducing the pain of patients and their families, – Developing the sense of self-confidence and self-efficiency in sick patients, – Developing the sense of motivation among voluntary groups of people to care about health and accompany with medical centers, and – Searching for talented pediatric patients to help them focus on their talent and develop it.

*Nima Rezaei*



*Closing Session*



**Host:** Ismail Reisli (*ireisli@hotmail.com*)  
**Venue:** Titanic Lara Otel  
**Main topic:** J Project Meeting on the Day of Immunology

## PROGRAM

13.00–14.00 Öğle yemeği (Lunch)  
Başkan: Prof. Dr. Gunnur Deniz, İsmail Reisli  
14.00–14.30 Türkiye’de J Project Toplantıları  
Prof. Dr. İsmail Reisli  
14.30–15.00 Artemis Deficiency  
Dr Esra Hazar Sayar  
15.00–15.30 Discussion

## SUMMARY

As 29 of April is the Day of Immunology, we had organized a J Project Meeting in Antalya during our National Immunology Congress (April 26–30, 2015).

J Project Meeting of Immunology Day (April 29, 2015) was primarily focused on the J Project Meetings in Turkey, and also awareness, clinical signs and treatment of PID among the physicians, also to discuss the importance of early diagnose in PID, and had two Turkish lectures as a panel.

More than 50 participants attended the meeting. The meeting was started with an opening lecture by Prof. Dr. Ismail Reisli from Konya focused on the J Project Meetings in Turkey between 2009 and 2015. He mentioned the high consanguinity rate of the parents of Turkish PID patients. He also noticed that the immunology centers were mainly located in the west of the country although the majority of the PID patients were from the east of the country. Besides that, the East Anatolia J Project was started.

Another lecture was presented by Esra Hazar Sayar about the clinical characteristics of the patients with Artemis Deficiency. She also talked about the clinical signs and the importance of early diagnosis for the PID patients.

I would like to thank all speakers and participants for their contributions, especially Turkish Society of Immunology for their financial help which made it possible to organize this event.

*Ismail Reisli*



*E. Hazar Sayar  
giving her lecture*



*I. Reisli as “Captain  
of Titanic”*



**Hosts:** Irina Snimshchikova (*snimshikova@mail.ru*)

**Venue:** The Medical Institute of Orel State University

**МИНИСТЕРСТВО ОБРАЗОВАНИЯ И НАУКИ РОССИЙСКОЙ ФЕДЕРАЦИИ**  
 ФЕДЕРАЛЬНОЕ ГОСУДАРСТВЕННОЕ БЮДЖЕТНОЕ ОБРАЗОВАТЕЛЬНОЕ УЧРЕЖДЕНИЕ ВЫСШЕГО ПРОФЕССИОНАЛЬНОГО ОБРАЗОВАНИЯ  
**"ОРЛОВСКИЙ ГОСУДАРСТВЕННЫЙ УНИВЕРСИТЕТ"**  
 МЕДИЦИНСКИЙ ИНСТИТУТ  
**МЕДИЦИНСКИЙ УНИВЕРСИТЕТ ДЕБРЕЦЕНА (ВЕНГРИЯ)**  
 ОТДЕЛЕНИЕ ИНФЕКЦИОННОЙ И ПЕДИАТРИЧЕСКОЙ ИММУНОЛОГИИ  
**ДЕПАРТАМЕНТ ЗДРАВООХРАНЕНИЯ ОРЛОВСКОЙ ОБЛАСТИ**  
 БЮДЖЕТНОЕ УЧРЕЖДЕНИЕ ЗДРАВООХРАНЕНИЯ ОРЛОВСКОЙ ОБЛАСТИ  
**"ДЕТСКАЯ ОБЛАСТНАЯ КЛИНИЧЕСКАЯ БОЛЬНИЦА им. З.И. КРУГЛОЙ"**  
 МЕДИЦИНСКАЯ ПАЛАТА ОРЛОВСКОЙ ОБЛАСТИ



**МЕЖДУНАРОДНЫЙ ОБРАЗОВАТЕЛЬНЫЙ ПРОЕКТ**  
**по первичным иммунодефицитам – J Project.**

## PROGRAM

School for practitioners.

### May 15–16

New concepts in the sphere of immunodeficiencies.

*Laszlo Marodi (the J-project organizer, Debrecen, Hungary)*

Practical approaches to the immunodeficiency states diagnostics.

*MD, professor Prodeus Andrey Petrovich (Moscow).*

New ways of immunodeficiency states diagnostics in pediatrics and neonatology.

*PhD, associate professor Korsunskiy Ilya Anatolyevitch (Moscow).*

Differential diagnostics of severe congenital neutropenia.

*MD, professor Rumyantsev Sergei Aleksandrovich (Moscow)*

Recurrent nettle-rash and angioedema: clinical picture, diagnostics, treatment.

*MD, professor Prodeus Andrey Petrovich (Moscow).*

Angioneurotic oedema modern therapy.

*Kuzmina Svetlana Yurievna (Moscow).*

Sickly children: the potential for immunotherapy optimization.

*MD, professor Snimshchikova Irina Anatolyevna (Orel).*

Polypragmasy and rational therapy of sickly children.

*MD, professor Prodeus Andrey Petrovich (Moscow).*

The urgency of the primary immunodeficiencies register creation in the Orel region.

*Fissyun Ivan Vladimirovich, Fomichev Vitaly Igorevich (Orel).*

### **Organizers:**

- 1) The Ministry of Education and Science of the Russian Federation
- 2) The Medical Institute of Orel State University
- 3) The Medical University of Debrecen (Hungary). The Department of Infectious and Paediatric Immunology.
- 4) The Department of Healthcare of Orel region.
- 5) The Regional Paediatric Clinical Hospital named after Z.I. Kruglaya.
- 6) The Medical Chamber of Orel region.

The international educational project on primary immunodeficiencies – J-Project was held in Orel, Russia on May 15-16 2015. The participants were the scientists from the leading medical centers of Russia, and the Head of the J-project – Professor Laszlo Marodi from Hungary.

J-Project is a well-known information campaign meaning conferences in different countries pursued by the East European Centre of paediatric and infectious immunology. The project takes place in more than 30 countries and unites fifty cities. Worldwide this program is highly appreciated, recognized, gives deep knowledge in post-graduate education of doctors in studying such field of medicine as primary immunodeficiency.

‘– The immune system disease now has more than three hundred forms to diagnose and they require deep knowledge of both molecular and clinical aspects’ - said Laszlo Marodi, head of the J project. - Our project aims to convey the latest developments in this area of specialists: immunologists, internists, paediatricians.

‘– According to the Russian statistics there should be approximately 80 patients with this diagnosis in the Orel region, according to the American one – 10 times more. Do you know how many registered? Only six... - said Vitaly Fomichev, the participant of the educational project, an allergist-immunologist of paediatrician hospital. ‘Thus, it turns out that there is insufficient diagnosis of patients. We believe that a special register should be made to include in every patient diagnosed with “primary immunodeficiency”’. To solve the problem of hypodiagnosics, the regional paediatricians were invited to participate in the project. Because primary care physicians often encounter the “sickly child”, and we are to diagnose the children with primary immunodeficiencies in this category especially. It is up to paediatrician to diagnose and to direct a child to an immunologist for further treatment.

*Irina Snimshchikova*



*Opening talk by László Maródi*



*The audience of the first J Project conference in Orel*



*László Maródi, Irina Snimshchikova, Sergei Rumyantsev, Elena Latysheva, Andrey Prodeus, Ivan Fissyun, Ilya Korsunskiy, Vitaly Fomichev, Tamara Vassina*



**Host:** Ismail Reisli (*ireisli@hotmail.com*)  
**Venue:** NG Sapanca Otel  
**Main topic:** From laboratory testing to the diagnosis of PID

## PROGRAM

13.00-14.00 Öğle yemeği (Lunch) Başkan: Prof. Dr. Yıldız Camcıoğlu, İsmail Reisli	14.20-14.40 Hipogammaglobulinemi, Hipokomplementemi Prof. Dr. İsmail Reisli
14.00-14.20 Lenfopeni Prof. Dr. Yıldız Camcıoğlu	14.40-15.00 Nötropeni Prof. Dr. Mustafa Yılmaz
	15.00-15.30 Discussion

## SUMMARY

We had organized a J Project Meeting in Sakarya during a Pediatric Asthma Meeting to increase the the awareness of primary immunodeficiency (PID) diseases among the physicians. The main topic of Sakarya Meeting was ‘From laboratory testing to the diagnosis of PID’, and had threeTurkish lectures as a panel.

Sakarya J Project Meeting was held on May 17, 2015 in Turkey. Sakarya City is located in the Northern East of Turkey and has a lake named as Sapanca, and also a forest near the lake. All participants had a sight-seeing tour to visit the natural ambience of a part of Sapanca Forest in early morning before meeting. The meeting was organized in NG Sapanca Hotel and was primarily focused on the awareness, clinical signs and treatment of PID among the physicians (especially pediatricians), also to discuss the importance of early diagnose in the patients with PID. More than 40 participants attended the meeting. Prof Yıldız Camcıoğlu from İstanbul University gave a lecture on the importance of lymphopenia for the diagnosis of PID. Prof. Dr. Ismail Reisli from Konya gave a lecture on Hypogammaglobulinemia and Complement Deficiencies, and Prof Mustafa Yılmaz from Adana talked about neutropenia. In discussion, all of the participants discussed the importance of early diagnosis and early treatment of PID. I would like to thank all participants and speakers for their contribution.

*Ismail Reisli*



*I. Reisli and N. Mahruki (mountain climber)*



*Sight-seeing tour to the Sapanca Forest*



**Hosts:** Liudmyla Chernyshova (*chernyshova@ukr.net*)  
**Venue:** Zhytomir Institute of Nursing  
**Main topic:** Diagnosis and Treatment of Primary Immunodeficiencies

## PROGRAM

### May 21

12.00 Opening of XI international scientific and practical symposium “Early diagnosis criteria of primary immunodeficiencies” within Central and Eastern European program “J-project”  
 Greeting of participants.

12.15 Seminar-school “Early diagnosis criteria of primary immunodeficiencies”

*L.I. Chernyshova (Kiev, Ukraine)*, Child’s Immunodeficiency Diseases in Ukraine, Condition on January 1, 2015  
*A.R. Rybakov (Kiev, Ukraine)*, Immunotherapy of Primary Immunodeficiencies: History and Prospects

13.00–13.30 Work in groups

Moderators: *L.V. Kostyuchenko (Lviv, Ukraine)*, *A.V. Bondarenko (Kiev, Ukraine)*, *F.I. Lapii (Kiev, Ukraine)*, *Y.S. Stepanovskiy (Kiev, Ukraine)*, *Y. Romanyshyn (Lviv, Ukraine)*, *H.M. Hilfanova (Kiev, Ukraine)*, *I. Savchak (Lviv, Ukraine)*, *S.A. Yakymovych (Kiev, Ukraine)*, *I.A. Hladun (Zhytomyr, Ukraine)*, *T.V. Oskina (Mykolaiv, Ukraine)*, *I.S. Sychova (Dnipropetrovsk, Ukraine)*, *H.S. Benko (Ivano-Frankivsk, Ukraine)*, *O.V. Stynych (Mukachevo, Ukraine)*, *L.D. Nikonets (Chernihiv, Ukraine)*, *I.F. Kimlyk (Cherkasy, Ukraine)*, *L.I. Nazarenko (Cherkasy, Ukraine)*, *O.I. Malko (Rivne, Ukraine)*, *N.E. Hryniowa (Vinnytsia, Ukraine)*, *S.O. Kaliuzhka (Chernihiv, Ukraine)*, *D.V. Osypchuk (Kiev, Ukraine)*.

13.30–14.30 Group speakers’ reports, work with experts

Experts: *L.I. Chernyshova (Kiev, Ukraine)*, *A.P. Volokha (Kiev, Ukraine)*, *N.I. Vasylenko (Kherson, Ukraine)*, *L.M. Dmytrash (Ternopil, Ukraine)*, *H.V. Peresoliak (Uzhhorod, Ukraine)*, *T.M. Polych (Poltava, Ukraine)*, *L.I. Samoilenko (Odesa, Ukraine)*, *L.V. Troparchuk (Khmelnitskyi, Ukraine)*, *O.V. Rabosh (Kiev, Ukraine)*

13.30–14.30 Parallel section of non-governmental patient organization “Rare Immune Diseases” (NGO-RID)

14.30–15.00 Break

15.00 First session of XI international scientific and practical symposium “Early diagnosis criteria of primary immunodeficiencies” within Central and Eastern European program “J-project”

Chairmen: *L.I. Chernyshova*, *M.V. Belevtsev*, *A.P. Volokha*, *L.V. Kostyuchenko*.

15.00–15.20 *A.P. Volokha (Kiev, Ukraine)* Syndromic Hypogammaglobulinemia

15.20–15.40 *N.I. Vasylenko (Kherson, Ukraine)* Wiskott-Aldrich Syndrome Autoimmune Manifestations, Treatment Problems

15.40–16.00 *M.V. Belevtsev (Minsk, Republic of Belarus)* TREK and KREK Determination for Perinatal Screening of PID

16.00–16.20 *S.O. Sharapova (Minsk, Republic of Belarus)* Genetic Characteristics of Lymphoproliferative Syndrome in PID

16.20–16.40 *L.V. Kostiuchenko (Lviv, Ukraine)* Family Case of Nijmegen Syndrome

16.40–17.00 *N.E. Hryniowa (Vinnytsia, Ukraine)* Primary care physicians informing about children with PID in Vinnytsia oblast

17.00–17.20 *Y. Romanyshyn (Lviv, Ukraine)* Hereditary Angioedema Syndrome

17.20–17.40 *Y.S. Stepanovskyi (Kiev, Ukraine)* First Diagnosed Case of Hyper-IgD Syndrome in Ukraine

17.40–17.45 *A.V. Bondarenko (Kiev, Ukraine)* Social Aspects of Primary Immunodeficiencies

17.45–18.00 *H. Pavuk (Chernivtsi, Ukraine)* Information about NGO “Rare Immune Diseases” Work

18.00–18.30 Discussion

## **May 22**

Second session

10.00–12.00 Meeting of the Ukrainian Association of Pediatric Immunology. Discussion of amending the Statute of the organization

12.00 Closing of symposium

## **SUMMARY**

Within Central and Eastern European program “J-project” XI international scientific and practical symposium “Early diagnosis criteria of primary immunodeficiencies” took place on May 21-22, 2015 in Zhytomyr, Ukraine. Traditionally, the symposium was organized by Pediatric Infectious Diseases and Pediatric Immunology Department of Shupyk National Medical Academy of Postgraduate Education (Head - Liudmyla I. Chernyshova, PhD, MD, DrSci, Professor) with the assistance of Zhytomyrska oblast state administration and Ukrainian manufacturer of preparation for substitution therapy by intravenous immunoglobulin PJSC “Biofarma”.

Doctors of different specialties from Zhytomyrska oblast and other regions of Ukraine, generally pediatricians, family doctors, pediatric immunologists, allergists, epidemiologists, infectionists, pulmonologists were present at the conference. There were also present leading Belarusian scientists in pediatric immunology - M.V. Belevtsev and S.O. Sharapova.

At the beginning of the symposium Chief Freelance Expert of the Ministry of Health of Ukraine in Pediatric Immunology and Head of Ukrainian Association of Pediatric Immunology L.I. Chernyshova revealed achievements and problems related to diagnosis and treatment of primary immunodeficiencies in Ukraine and abroad. Currently, 17 patients in Ukraine underwent stem cells transplantation (9 with severe combined immunodeficiency, 7 with Wiskott-Aldrich syndrome, 1 with DOCK8 deficiency), 83.3% of which were successful. 813 patients were brought in primary immunodeficiencies patients registry of Ukraine. A centralized purchase of preparations for substitution therapy is made for children with antibody production deficiency. Unavailability of genetic diagnosis and allogenic transplantation of stem cells from unrelated donor still remain the basic problems of immunology in Ukraine. Making non-governmental patient organization “Rare Immune Diseases” is one of the last year’s achievements.

The seminar-school program had two parts: work in groups and plenary session.

Each group got some tasks about primary immunodeficiencies aspects and worked out a problem solving plan. The plenary session included lectures and reports of leading scientists from Ukraine and Belarus about primary immunodeficiencies.

The meeting was marked by ease and friendly atmosphere thanks to organizers' hospitality.

At the end of seminar the participants visited the castle "Radomyshl" which impressed by its picturesque ensemble of architecture and scenery. Everyone was also amazed by a collection of icons of different periods from all over Ukraine.

*Liudmyla Chernyshova*



*L. Chernyshova, A. Volokha  
and L. Kostyuchenko*



*Working group session*



*Plenary session*



*A. Volokha, A. Hilfanova, M. Belevtsev,  
O. Rabosh, L. Chernyshova, S. Sharapova,  
A. Bondarenko, S. Yakymovych*



*Icon viewing at Radomyshel Museum*



**Host:** Tadej Avčin (*tadej.avcin@kclj.si*)**Venue:** University Children's Hospital Ljubljana

## PROGRAM

### May 23

Patient with chronic disease of immune system and school

Slovenian association for children with immune diseases – Activities

*Prof. dr. Tadej Avčin*

Children with immune diseases – School issues

*Dr. Nataša Toplak*

Children with immune diseases – Hospital school

*Metoda Leban Dervišević*

Children with immune diseases – Psychological aspects of chronic illness

*Mateja Gorenc*

A report from meeting of National societies of patients with rheumatic diseases

*Mirjam Kepić*

A report from meeting of National societies of patients with PID

*Sandra Šparaš*

## SUMMARY

Traditional meeting for children with immune diseases and their parents was held on 23rd May in Ljubljana, Slovenia (organized by the Slovenian association for children with immune diseases). Scientific program was focused on education of patients with immune diseases. Common difficulties in education process and suggestions to overcome them were presented.

Children enjoyed competing in games that require different skills: bowling, fishing paper fishes, carrying balls in spoon and throwing balls through holes. During buffet lunch, parents and health care workers had an opportunity to discuss different aspects of disease and share ideas for future.

*Tadej Avčin*



*Clown doctors entertaining participants*



*Patients and parents attending lectures*

**Host:** Areg Totolyan (*totolian@pasteurorg.ru*)

**Venue:** Hall Michalovskij

## PROGRAM

### June 3 (wednesday)

11.30–14.30 Satellite symposium “primary immunodeficiency” (first session)  
(International Educational Project on PID – J-Project)

Chairpersons: *professor László Maródi* RAS corresponding member, professor Areg Totolyan

11.30 The evolving view of IL-17-mediated immunity in defense against mucocutaneous candidiasis in humans  
*László Maródi (Debrecen, Hungary)*

12.10 Primary Immunodeficiency – today’s reality  
*Irina Tuzankiina (Yekaterinburg, Russia)*

12.30 A new immunodeficiency caused by hyperactivation of the PI3K pathway signaling  
*Anne Durandy (Paris, France)*

13.10 Effect of rituximab for the treatment and diagnosis of primary immunodeficiency in children

*Mikhail Belevtsev (Minsk, Belarus)*

13.30 Risk of BCG infection in primary immunodeficiency children  
*Ewa Bernatowska (Poland)*

14.10 Immunological and genetic diagnosis of chronic lymphoproliferation  
*Svetlana Sharapova (Minsk, Belorussia)*

14.50–17.10 Satellite symposium “Primary immunodeficiency” (second session)  
(International Educational Project on PID – J-Project)

Chairpersons: *professor Andrey Prodeus (Moscow, Russia)* *professor Irina Kondratenko (Moscow, Russia)*

14.50 Gastrointestinal disorders and respiratory infections as leading symptoms of X-linked agammaglobulin-



*Speakers of the international PID symposium*

emia in children: 34 year experience  
of a single center  
*Malgorzata Pac (Poland)*  
15.30 Genealogical analysis of primary

immunodeficiency in adult patients  
*Karakina M., Tuzankina I. A. Sher-  
shnev V.N. (Ekaterinburg, Russia)*



*Marina Guseva giving her talk*



*Malgorzata Pac (left) and Ewa Bernatowska  
from Warsaw, Poland*



*Irina Kondratenko on an excursion boat on  
river Neva*



*Hydrometeorological Institute  
at Nobrezhnaya Makarova*



*Esther de Vries (left) and Irina Tuzankina  
co-chairing the J Project session*



*Areg Totolyan, organizer of the J Project  
Meeting*

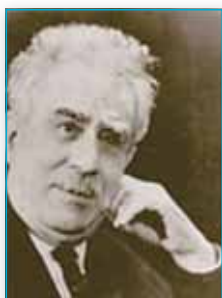
## IOFFE AWARD FIRST PRESENTED TO A NON-RUSSIAN CLINICAL IMMUNOLOGIST

Clinical Immunology was established as a medical discipline in Russia by Vladimir Ilyich Ioffe in the middle of the past century. To appreciate outstanding activity of professionals in the field, the North-Western Branch of the Russian Academy of Sciences jointly with the Allergology and Clinical Immunology Society of Russia established the prestigious Ioffe award in 2003. The award had been offered once a year to one Russian immunologist until 2015. László Maródi was the first non-Russian immunologist who received the Ioffe award as an acknowledgement for his long term activity and achievements to improve clinical immunology in general, and primary immunodeficiency patient care and research, in particular, in June 2015 in St. Petersburg.

Russia joined the J Project in 2007 when Maria Guseva and Areg Totolyan organized the first J Project meeting in St. Petersburg. Later on more than 20 meetings were organized in Ekaterinburg, Moscow, St. Petersburg and elsewhere in Russia to improve awareness on PID disorders, patient care and treatment. Russia has also been active in clinical research collaboration coordinated by the J Project. Doctors from Ekaterinburg, Moscow and St. Petersburg have also participated in the J2 Project program aimed at training professionals in genetic sequencing technologists in Debrecen so that they would contribute genetic diagnostics of PID patients in their own center.



*V. Ioffe certificate and plackett*



*Vladimir I. Ioffe  
(1898–1974)*

In 1945 the Department of Microbiology and Immunology was organized under the supervision of Vladimir I. Ioffe. Ioffe laid the foundation of the clinical and experimental immunology in Russia. In late 1940s and during 1950s its work was aimed at studying of juvenile droplet infections in microbiology and immunology as well as general problems of immunity. Later the Department staff concentrated its attention on chronic infections, primarily of streptococcal etiology, problems of experimental and clinical immunology, as well as problems of general immunology

*Areg Totolyan*



**Host:** Irina Tuzankina (*ituzan@yandex.ru*)

**Venue:** House of Diaghilev

## PROGRAM

The evolving view of il-17-mediated immunity in defense against mucocutaneous candidiasis in humans

*László Maródi (Debrecen, Hungary)*

Small forms of immunodeficiency.

*Prodeus Andrei (Moscow)*

Primary immunodeficiency in the Urals.

*Tuzankina Irina (Ekaterinburg)*

Defects of innate immunity

*Kondratenko Irina (Moscow)*

Approaches to the treatment of patients with primary immunodeficiency

*Latysheva Tatyana (Moscow)*

Diagnostics of primary immunodeficiency in the Perm region: history and prospects.

*Troitskaya Ekaterina (Perm)*

Register of children with PID in the Perm region.

*Smyshlyaeva Valentina (Perm)*

Clearly defined syndromes in PID register of Sverdlovsk region

*Elena Vlasova (Ekaterinburg)*

Svetlana Deryabina. PID and screening research programs at newborns

*Michael Bolkov (Ekaterinburg)*

Case of chronic granulomatous disease at the girl of 1 year 11 months.

*Cheremnyh Lyubov (Perm)*

Crohn's disease – primary immunodeficiency.

*Karakina Marina (Ekaterinburg)*

Giperimmunoglobulinemia-D at a boy of 10 years

*Smyshlyaeva Valentina (Perm)*

## SUMMARY AND CONCLUSION

Perm – a city in the east of the European part of Russia, in the Urals region, the administrative center of Perm region, a port on the Kama River, the transport hub on the Trans-Siberian Railway, a major industrial, scientific, cultural and logistics center of the Urals. Many participants noted the warm, unique, friendly atmosphere of the conference, which took place in a modern, well-equipped complex - academic high school №11 (House of Diaghilev). Diaghilev's House is a cultural and historical center, built to commemorate the name of famous Russian enterpriser, thanks to whom in the beginning of the 20th century Russian ballet became world famous.

Forum J Project was held within the XII Urals Conference of Immunology and II Russian School of Young Scientists “Modern Problems of Microbiology, Immunology and Biotechnology”, which featured more than 140 presentations in the following areas: autoimmunity, differentiation of immune cells, cytokines and Cytokine therapy, diagnostic systems, immunopharmacology and medical chemistry, immune regulation, immunology of reproduction, genomics immunity, primary immunodeficiencies, pathology and immune system, HIV infection, ecology and genetics of microorga-

nisms, biotechnology. The forum was attended by over 300 people from 38 cities of Russia, as well as Israel and Slovenia.

Greeting speech to the Forum was held by President of Russian Society of Immunology Academician Valery Chereshnev; Deputy Chairman of the Government of Perm Region Kovtun Olga; Deputy Chairman of the Presidium of Perm Scientific Center of UB RAS Strelnikov Vladimir; Vice-Rector for Science PGMU Furman Eugene, director of the Institute of Ecology and Genetics of Microorganisms UB RAS Demakov Vitaly.

Posters were presented, a contest for young scientists was held, a round table on the diagnosis and exchange of experience in the treatment of primary immunodeficiencies was organized. It was decided to continue the coordination of the exchange of experience, the diagnostics and management of patients with PID and hold the next conference in Russia in Kaliningrad.

*Irina Tuzankina*



*Perm*



*The building (UL) and interior of the House of Diaghilev (venue of the J Project Meeting)*



*Conference in House of Diaghilev*



*Elena Vlasova*



*Valeriy Chereshev, Ivan Kozlov, Andrei Prodeus*



*Valeriy Chereshev , Irina Tuzankina*



*Svetlana Zamorina, Juliya Ziyatdinova*



**Host:** Margit Serban (*mserban@spitalcopiitm.ro*)  
 Mihaela Bataneant (*mihabataneant@yahoo.com*)  
**Venue:** Regional Business Center  
**Main Topic:** Actualities in Primary Immunodeficiencies

## PROGRAM

### September 3

Registration

19.00 Opening Ceremony at Romanian Opera

20.30 Welcome cocktail in Opera Hall

### September 4

Introduction

Presentations

Chairs: *Marodi L., Șerban M., Gherghina I.*

Primary immunodeficiencies. Current concepts and future challenges  
*Marodi L. (Debrecen)*

Progress in diagnosis and treatment of primary immunodeficiencies  
*Gherghina I., Cochino A., Damir P., Matei D. (Bucharest)*

Primary immunodeficiencies – the cinderella of immunology?  
*Serban M., Bataneant M., Baica M. (Timisoara)*

Symptomatic selective IgA deficiency in children  
*Rugină A., Alexoae M., Ioniuc I., Petruț T. (Iasi)*

Clinical cases of immunodeficiencies from IOMC  
*Cochino A., Covaci S., Farkas O., Gherghina I. (Bucharest)*

Hematopoietic stem cell transplantation for primary immunodeficiencies. The experience of the transplant center Timisoara  
*Jinca C., Serban M., Bataneant M.,*

*Oprisoni A., Isac A., Pascallau A., Balan A., Ciocarlie O., Baica M., Arghirescu S. (Timisoara)*

Treatment difficulties in children with primary immunodeficiencies. Clinical cases

*Iurian S., Fintina D. (Sibiu)*

Biological reactivity to pneumococcal test vaccination in children with selective immunoglobuline A deficiency  
*Ellenes-Jakabffy Z.I., Maródi L.2 (IOradea, 2Debrecen)*

Hypogammaglobulinemia – major sign in primary immunodeficiencies diagnosis

*Bataneant M. (Timisoara)*

ARPID – between hopes and achievements

*Baldea A. (Romanian Association of patients with primary immunodeficiencies – ARPID)*

Discussion, remarks, conclusions

Lunch

POSTERS

Thursday, September 3 and Friday, September 4

Psoriasis vulgaris in child – case presentation

*Singer C., Cosoveanu S., Stoica L., Oancea G., Dragomir F., Dumitru B., Cristea C. (Craiova)*

Clinical and biological particularities in Stevens-Johnson syndrome

*Dop D., Niculescu E., Puiu I., Moroșanu A., Marinău L. (Craiova)*

Congenital neutropenia associated with renal malformation

*Pittner A., Marodi L., Toth B., Boeriu E., Pop M., Preja M., Manzat L., Lelik M., Baica M., Serban M., Bataneant M. (Timisoara, Debrecen)*

Celiac disease – one of the face of IgA deficiency

*Cozma I., Belei O., Pop M., Popa M., Arghirescu S., Lesovici M., Boeriu E., Bataneant M. (Timisoara)*

Cellular cooperation is essential for antibodies production – illustrated by a clinical case

*Zaica C., Marodi L., Toth B., Cucuruz M., Baica M., Boeriu E., Manzat L., Serban M., Hohl L., Bataneant M. (Timisoara, Debrecen)*

Diagnostic difficulties in a case of HLH

*Pescaru L., Cucuruz M., Bataneant M.,*

*Lelik M., Serban M., Arghirescu S., Boeriu E. (Timisoara)*

Generalized BCG-itis – a suggestive sign for SCID

*Preja M., Pop M., Pascalau A., Miculschi G., Ritli L., Baica M., Arghirescu S., Marodi L., Serban M., Bataneant M. (Timisoara, Debrecen)*

Autoimmune encephallitis – a possible face of a PID

*Popa C., Bacos C., Badeti R., Izvernariu F., Popoiu A., Serban M., Cozma I., Bataneant M. (Timisoara)*

Chronic thrombocytopenia in infancy – presentation form for Wiskott-Aldrich syndrome

*Petrescu C., Bataneant M., Marodi L., Aiuti A. Cicalese M., Serban M. (Timisoara, Debrecen, Milan)*

## SUMMARY

On September 3-4, 2016, The 130th J Project Meeting was held in Timisoara, Romania. The meeting was organized by the Departments of Hematology and Immunology, IIIrd Pediatric Clinic, University of Medicine and Pharmacy “Victor Babes” and Children’s Clinical Emergency Hospital “Louis Turcanu” Timisoara under umbrella of The XIIth Romanian Pediatric Congress, with more than 1000 participants including, pediatricians, general practitioners, laboratory doctors, hematologists, residents from all region of Romania.

The J Project Meeting was entitled “Actualities in Primary Immunodeficiencies”, the main aims being to increase and broaden knowledge of PID, to establish professional collaboration with other centers, to facilitate early diagnosis and treatment. The invited speaker was Prof. Dr. Laszlo Marodi (Debrecen, Hungary) who gave an interesting overview regarding PID achievements and current concepts. Prof. Dr. Margit Serban (Timisoara) presented the actual situation of PID National Data Base and the difficulties of diagnosis and treatment of PID patients in our country. Bone marrow transplantation in Romanian PID patients and the broad spectrum of hypogammaglobulinemia were another important objectives of this meeting.

The second part of the meeting contained a series of difficult PID case presentation giving opportunity for collegial discussion in friendly atmosphere. The patient’s organization – ARPID was an important part of this meeting, and its president gave us information about their achievements and activities.

The third part consisted in a lot of very interesting poster viewing. The poster “Chronic thrombocytopenia in infancy – presentation form for Wiskott-Aldrich syn-

drome” was awarded with the 1st prize at The XIIth Romanian Pediatric Congress.

The scientific and social programs of this meeting were highly successful and we would like to thank to all participants, especially our distinguished invited speaker, Prof. dr. Laszlo Marodi.

There is no doubt that J Project Meeting in Timisoara was a very important scientific event in the field of PID and the collaboration with the Pediatric Infectology and Immunology Center Debrecen, gave us the opportunity to improve the level of the diagnosis and treatment of PID in Romania.

*Mihaela Bataneant*



*Aurica Rugina from Iasi presenting a difficult case of combined immunodeficiency*



*Ioan Gherghina (R) from Bucharest presenting actualities in PID. Margit Serban and László Maródi chairing the session.*



*Summer camp 2015 for PID patients (children and adults), Paltinis, Sibiu*



*April 22 2015, WPIW celebration in front of the Children's Hospital "Louis Turcanu" Timisoara*

**Host:** Nima Rezaei (*rezaei\_nimia@yahoo.com*)

**Venue:** Health and Art (HEART) Group, Andisheh Cultural Hall

## PROGRAM

The “Health and Art” group, an active interesting group of Universal Scientific Education and Research Network (USERN) hold the First International Festival of Pediatric Patients’ Paintings (IFPPP) on the International Children’s Day by the cooperation of more than 60 universities, institutes, art and medical centers.

The first IFPPP was organized during the Children’s Week (October 3rd–9th, 2015), while the date of ceremony of awardees was is the Children’s Day (October 8th, 2015). The 1st IFPPP was organized in Tehran, Iran, hosted by Tehran University of Medical Sciences; meanwhile at the closing ceremony, the Ambassador of Hungary kindly announced hosting the 2nd Festival in 2016 in the respected country. J Project is one of the supporters of the IFPPP.

Children and teenagers under 18 with chronic diseases and/or who were hospitalized at least once were supposed to send their painting to the end of August 23rd, 2015 (Doctor’s day) in order to take part in the festival, and the topic of paintings was “health”.

Nine hundred and twenty eight artworks (paintings) were sent to festival department from 26 countries; after selection, 200 artworks were chosen for exhibition and being published in books.

Simultaneous exhibitions were organized in 30 cities during the week in different countries.

Among selected paintings, paintings were organized and selected according to different ages, and during the ceremony which was held in October 8th, 2015 children and teenagers received their awards.

The closing ceremony was held by the presence of children from Iran, Spain, Lebanon, Slovenia, Belarus, Azerbaijan, Germany, and India.

Ambassadors of Hungary, Egypt, Lebanon, Iraq and the second runners of Germany and India, and Iran’s Minister of Health and Medical Education, the chancellor



*Poster of the Festival*



*Countries that contributed to the Festival*



of Tehran University of Medical Sciences, artists and illustrators who work at children's areas were the special guests of the ceremony.

The closing ceremony started with the children and teenagers' performance who read the Ferdowsi's Shahnameh, while two other teenagers were performing songs, and another teenager was painting on the stage.

When awards and prizes were given to children and teenagers, all officials who were at ceremony gave trophies and prizes to winners, and children were happy that they could receive their prizes from officials.

Since the winners of Germany and India were not present at the ceremony, the delegates of those countries received the prizes to give them and thank them for taking part in this festival.

At the end of the ceremony, the ambassador of Hungary revealed the poster of the second festival, and announced that the host of the second festival will be Hungary.



*Simultaneous exhibition of selected paintings in 30 cities worldwide*

*Nima Rezaei*



*N. Rezaei, President of Festival,  
A. Jafarian, Chancellor of TUMS and  
H. Ghazizadeh Hashemi, Minister of Health  
and Medical Education*



*Winners: 1-6 yrs: Mohammad Aryan Ghazvinian (5 yrs): Iran, Evinas Vencus (6 yrs): Lithuania, Baran Zareian (5 yrs): Iran, Maryam Aleyeva (4 years): Azerbaijan, 7-10 yrs: Max Lennart (9 yrs): Slovenia, David Alexandru (10 yrs): Romania, Amir Mohammad Bahmadi (10 yrs): Iran, 11-14 yrs: Paulina Schultz (13 yrs): Germany, Elin Serkisian (12 yrs): Iran, Alba Begara Valera (12 yrs): Spain, 15-18 yrs: Zahra Farasmaneh (16 yrs): Iran, Neha Rey (16 yrs): India, Maryam Ali Debouk (15 yrs): Lebanon*



**Host:** Anna Sediva (*Anna.Sediva@fnmotol.cz*)**Venue:** Kraví Hora, Bořetice, South Moravia**Main Topic:** Immunodeficiencies update

## PROGRAM

### Morning session

9.15 – 12.00 Hummoral immunodeficiencies

chairs: *Anna Šedivá, Tomáš Freiburger, Jiří Litzman*

Humoral immunodeficiencies. (20 min.)  
*Pavlaína Králíčková*

Pneumopatologies in CVID. (20 min.)  
*Tomáš Milota*

CVID and autoimmunity. (20 min.)  
*Andrea Poloučková*

Diagnostics of PIDs. (20 min.)

Coffee Break

Immunoglobulin therapy. (20 min.)  
*Radana Zachová*

Octapharma  
*Radana Zachová, Tomáš Milota, Jana Kayserová, Andrea Poloučková*

SC immunoglobulins, practical aspects.

Discussion

12.00–13.00 lunch

### Afternoon session

13.00–16.00 Cellular Immunodeficiencies

chairs: *Jiří Litzman, Andrea Poloučková, Anna Šedivá*

Screening SCID + news in PIDs. (20 min.)  
*Renata Formánková*

Stem cell transplant in PIDs. (20 min.)  
*Tomáš Kalina*

EuroFlow PID. (20 min.)  
*Tomáš Freiburger*

Genetics in PIDs. (20 min.)

Coffee break

NGS in PIDs. (20 min.)  
*Froňková Eva*

APDS. (20 min.)  
*Adam Klocperk, Jana Kayserová, Radana Zachová, Tomáš Milota*

Hypogammaglobulinemia in severe atopic dermatitis. (20 min)

*Jana Kayserová*

## SUMMARY

The meeting was a continuation of series of educational events, organized under the scheme of JMF center networks and J project events targeted at an education in primary immunodeficiencies.

The target audience is formed by physicians from local region. The meeting is also an occasion for an annual meeting of Interest group in primary immunodeficiencies, associated with the Czech Society for Allergy and Immunology.

The program of the meeting is attached, main topics covered several aspects of PIDs, including novel recent findings especially in genetics of PIDs.

### Plans for 2016

Our 2016 meeting in 2016 will take place in Western Bohemia, and will be organized as a satellite of annual congress of the Czech society for Allergy and Clinical Immunology, in Plzeň, 12.–15.10.2016.

*Anna Sediva*



*Anna Sediva presenting her talk*



*The audience at the J Projcet meeting*



*View of Bořetice, Moravia*



*View of Bořetice*

**Host:** Marianna Murdjeva ([mmurdjeva@yahoo.com](mailto:mmurdjeva@yahoo.com))  
**Venue:** Department of Microbiology and Immunology,  
 Medical University-Plovdiv, Auditorium building  
**Main topic:** PID forum within 70 years Anniversary of the Department  
 of Microbiology and Immunology, MU-Plovdiv

## PROGRAM AND SUMMARY

The 70 years Anniversary of the Department of Microbiology and immunology, MU-Plovdiv, was organized on 20 November 2015 in Plovdiv. Bulgarian immunologists, pediatricians and medical students attended the meeting. The focus was directed to the achievements of the Department of Microbiology and Immunology during the last decades for the benefit of students' education and patients' health in the field of immunology and microbiology. Special attention was put on the activities of the Department together with the Bulgarian Associations of Clinical Immunology and Microbiology for the early diagnosis, prevention and treatment of PID and the associated infections. The participation in J project was again pointed out highly for better management of Bulgarian PID patients.

*Marianna Murdjeva*



*The lecture by M. Murdjeva was focused on 70th Anniversary of the Department of Microbiology and Immunology*



*A service of health of Bulgarian PID patients, medical doctors and nurses involved in the diagnosis and treatment of PID. The candle lights symbolize the hope of better management and control of PID*



*View of Plovdiv*





**Host:** Georgina Kuli-Lito (*gkuli\_lito@hotmail.com*)

**Venue:** Hotel Adriatic, Durres

## PROGRAM

9.30–10.00 A stepwise approach for PID diagnosis: Increasing the awareness of a not so uncommon condition in the pediatric practice.

*Genc Sulcebe*

10.00–10.30 Immunological and cytogenetic findings in children with chromosome instability syndromes.

*Anila Babameto-Laku*

10.30–11.00 Malignancies and Immunodeficiencies: Implications for Hematologists / Oncologists.

*Donjeta Bali*

12.30–13.00 HPV immunization in a patient with WHIM Syndrome.

*Kristina Mironsk a (Macedonia)*

13.00–13.30 Primary immunodeficiency in last five years.

Successes and shortcomings.

*Gjeorgjina Kuli-Lito*

13.30–14.00 Job syndrome-a rare immunodeficiency.

*Evda Vevečka*

14.00–14.20 Immunodeficiencies and the rheumatic diseases

*Gent Xhelili*

14.20–15.00 A case with congenital neutropenia and extrahematopoietic multi-systemic manifestations"-case report

*Sonila Boriçi*

15.00–15.20 A clinical aspect of the presentation of Bruton agammaglobulinemia.

*Ermela Celaj*

## SUMMARY

Albanian pediatric society, in collaboration with pediatric service of infectious diseases and J project, organized the symposium: "Primary immunodeficiencies, diagnostic and therapeutical challenge" The symposium was held on 21st November 2015, in City of Durres. The speakers presented papers of their practice with patients with PID. Except Albanian pediatricians, we had international invited lecturers from Macedonia and Kosovo. The activity was followed by 127 pediatricians and family doctors from all over the country. The objective of the meeting was to emphasize once more about the existence of PID and to stimulate the general pediatricians and family doctors to ask for such cases. Since the first J project meeting that we, had in Tirana, in April 2010, the number of PID diagnosed patients is increased more than twice. We have collected all the information and data base



*Participants of the Meeting*



of all patients to complete the national register and efforts are performed in order to establish the genetic diagnosis and improve the quality of life of these children. Here by, you have the program and some pictures of the symposium.

*Georgina Kuli-Lito*



*Kristina Mironska giving her lecture on WHIM syndrome*



*Get together after the meeting*



*View of Tirana*

## J Project Meetings 2004-2015

1. **Targu Mures**, Romania, March 11–12, 2004; Organizer: *Csilla Todea*
2. **Prague**, Czech Republic, May 10–11, 2004; Organizer: *Anna Sediva*
3. **Belgrade**, Serbia/Montenegro, June 11–12, 2004; Organizer: *Srdjan Pasic*
4. **Skopje**, Macedonia, September 17–18, 2004; Organizer: *Katarina Stavrik*
5. **Kiev**, Ukraine, November 18–19, 2004; Organizer: *Alla Volokha*
6. **Zakopane**, Poland, December 16–17, 2004; Organizer: *Ewa Bernatowska*
7. **Sofia**, Bulgaria, April 15–16, 2005; Organizer: *Elissaveta Naumova*
8. **Prague**, Czech Republic, May 9–10, 2005; Organizer: *Anna Sediva*
9. **Gdansk**, Poland, September 23–24, 2005; Organizer: *Ewa Bernatowska*
10. **Debrecen**, Hungary, November 4–5, 2005; Organizer: *László Maródi*
11. **Lviv**, Ukraine, November 25, 2005; Organizer: *Larysa Kostyuchenko*
12. **Oradea**, Romania, December 20, 2005; Organizer: *Zoltán Ellenés*
13. **Debrecen**, Hungary, January 16, 2006; Organizer: *László Maródi*
14. **Prague**, Czech Republic, May 8–9, 2006; Organizer: *Anna Sediva*
15. **Bucharest**, Romania, June 9–10, 2006; Organizer: *Nicolae Iagaru*
16. **Minsk**, Belarus, November 9–10, 2006; Organizer: *Mikhail Belevtsev*
17. **Debrecen**, Hungary, December 8–9, 2006; Organizer: *László Maródi*
18. **Zaporozhzhye**, Ukraine, Apr 19–20, 2007; Organizer: *Liudmyla Chernyshova*
19. **St. Petersburg**, Russia, May 29–30, 2007; Organizer: *Marina Guseva*
20. **Ohrid**, Macedonia, September 20–21, 2007; Organizer: *Kristina Mironska*
21. **Iasi**, Romania, October 12–13, 2007; Organizer: *Aurica Rugina*
22. **Ljubljana**, Slovenia, November 16–17, 2007; Organizer: *Tadej Avcin*
23. **Odessa**, Ukraine, April 10, 2008; Organizer: *Liudmyla Chernyshova*
24. **Sunny Beach**, Bulgaria, May 22–23, 2008; Organizer: *Elissaveta Naumova*
25. **Sarajevo**, Bosnia-Herzegovina, October 10–11, 2008; Organizer: *Velma Mulaosmanovic*
26. **Chisinau**, Rep. of Moldova, Oct. 31–Nov. 1, 2008; Organizer: *Lyudmila Cerempei*
27. **Riga**, Latvia, November 27–28, 2008; Organizer: *Tatjana Prokofjeva*
28. **Timisoara**, Romania, March 19–20, 2009; Organizer: *Margit Serban*
29. **Sevastopol**, Ukraine, April 9–10, 2009; Organizer: *Liudmyla Chernyshova*
30. **Ekaterinburg**, Russia, May 13–14, 2009; Organizer: *Irina Tuzankina*
31. **St. Petersburg**, Russia, June 9–10, 2009; Organizer: *Marina Guseva*
32. **Konya**, Turkey, June 25–26, 2009; Organizer: *Ismail Reisli*
33. **Krakow**, Poland, September 24–25, 2009; Organizer: *Danuta Kowalczyk*
34. **Tallinn**, Estonia, October 7–8, 2009; Organizer: *Sirje Velbri*
35. **Ljubljana**, Slovenia, October 9–10, 2009; Organizer: *Natasa Toplak*
36. **Tehran**, Iran, October 11–12, 2009; Organizer: *Asghar Aghamohammadi, Nima Rezaei*
37. **Cairo**, Egypt, October 18–19, 2009; Organizer: *Nermeen Galal*
38. **Minsk**, Belarus, October 22–23, 2009; Organizer: *Mikhail Belevtsev*
39. **Tirana**, Albania, April 8–9, 2010; Organizer: *Georgina Kuli-Lito*
40. **Porto Marina**, Egypt, April 16–17, 2010; Organizer: *Aisha El-Marsafy*
41. **Kharkov**, Ukraine, May 19–20, 2010; Organizer: *Liudmyla Chernyshova*

42. **Zlatibor**, Serbia, June 1–2, 2010; Organizer: *Srdjan Pasic*
43. **Zagreb**, Croatia, July 2–3, 2010; Organizer: *Darko Richter*
44. **Chelyabinsk**, Russia, August 30–31, 2010; Organizer: *Irina Tuzankina*
45. **Budapest**, Hungary, September 9–10, 2010; Organizers: *László Maródi, Miklós Szolnoky*
46. **Tehran**, Iran, October 11–12, 2010; Organizers: *Asghar Aghamohammadi, Nima Rezaei*
47. **Pushkin Hills**, Russia, February 3–4, 2011; Organizers: *Marina Guseva, Areg Totolian*
48. **Zakopane**, Poland, February 24–26, 2011; Organizer: *Ewa Bernatowska*
49. **Oradea**, Romania, March 1, 2011; Organizer: *Ladislau Ritli*
50. **Debrecen**, Hungary, March 10–11, 2011; Organizer: *László Maródi*
51. **Moscow**, Russia, March 31–April 1, 2011; Organizer: *Irina Kondratenko*
52. **Baku**, Azerbaijan, April 22–23, 2011; Organizer: *Gulnara Nasrullayeva*
53. **Bratislava**, Slovakia, April 28–29, 2011; Organizer: *Peter Ciznar*
54. **Lutsk**, Ukraine, May 11–12, 2011; Organizer: *Liudmyla Chernyshova*
55. **Sibiu**, Romania, June 10–11, 2011; Organizer: *Sorin Iurian*
56. **Chelyabinsk**, Russia, June 26–27, 2011; Organizer: *Irina Tuzankina*
57. **Ohrid**, Rep. Macedonia, October 8, 2011; Organizer: *Kristina Mironska*
58. **Tehran**, Iran, October 15, 2011; Organizer: *Nima Rezaei*
59. **Trabzon**, Turkey, November 19–20, 2011; Organizers: *Fazil Orhan, Ismail Reisli*
60. **Riga**, Latvia, November 26, 2011; Organizer: *Tatjana Prokofjeva*
61. **Lillafüred**, Hungary, January 20–21, 2012; Organizer: *Miklós Szolnoky*
62. **Budapest**, Hungary, January 27–28, 2012; Organizer: *Miklós Szolnoky, Judit Szabó*
63. **Rostov-on-Don**, Russia, March 16, 2012; Organizer: *Ludmila Sizyakina*
64. **Moscow**, Russia, March 29, 2012; Organizer: *Irina Kondratenko*
65. **Chernigov**, Ukraine, April 5–6, 2012; Organizer: *Liudmyla Chernyshova*
66. **Tallinn**, Estonia, April 19, 2012; Organizer: *Krista Ress*
67. **Tehran**, Iran, April 22, 2012; Organizers: *Asghar Aghamohammadi, Nima Rezaei*
68. **Bratislava**, Slovakia, April 27, 2012; Organizers: *Peter Ciznar*
69. **Diyarbakir**, Turkey; May 12, 2012; Organizer: *Ismail Reisli*
70. **Prague**, Czech Republic; May 14–15, 2012; Organizer: *Anna Sediva*
71. **Konya**, Turkey; May 26–27, 2012; Organizer: *Ismail Reisli*
72. **Warsaw**, Poland; 2012; Organizer: *Ewa Bernatowska*
73. **Sibiu**, Romania; June 1–2, 2012; Organizer: *Sorin Iurian*
74. **Tzigov Chark**; June 8–9, 2012; Organizer: *Elissaveta Naumova*
75. **Astana City**, Kazakhstan, June 12–15, 2012; Organizer: *Panteley Popandopulo*
76. **Tyumen**, Russia–Siberia, July 1–2, 2012; Organizer: *Irina Tuzankina*
77. **Ljubljana**, Slovenia, September 14–15, 2012; Organizer: *Tadej Avcin*
78. **Tehran**, Iran, October 13–14, 2012; Organizer: *Nima Rezaei*
79. **Timisoara**, Romania, October 25–26, 2012; Organizer: *Mihaela Bataneant*
80. **Minsk**, Belarus, November 17, 2012; Organizer: *Mikhail Belevtsev*
81. **Ufa**, Russia, November 23, 2012; Organizer: *Irina Tuzankina*
82. **Sanliurfa**, Turkey, November 25, 2012; Organizer: *Ismail Reisli*
83. **Krakow**, Poland, December 15, 2012; Organizer: *Ewa Bernatowska*

84. **Mukachevo**, Ukraine, April 18, 2013; Organizer: *Liudmyla Chernyshova*
85. **Tehran**, Iran, April 23, 2013; Organizer: *Nima Rezaei*
86. **Bratislava**, Slovakia, April 24, 2013; Organizer: *Peter Ciznar*
87. **Debrecen**, Hungary, April 26, 2013; Organizer: *László Maródi*
88. **Ljubljana**, Slovenia, May 9, 2013; Organizer: *Tadej Avcin*
89. **Prague**, Czech Republic, May 13–14, 2013; Organizer: *Anna Sediva*
90. **Moravia**, Czech Republic, May 31, 2013; Organizers: *Jiri Litzman, Anna Sediva*
91. **Budapest**, Hungary, May 31–June 1, 2013; Organizer: *László Maródi*
92. **Cracow**, Poland, September 20–21, 2013; Organizer: *Ewa Bernatowska*
93. **Szolnok**, Hungary, October 5, 2013; Organizer: *Zsuzsa Horváth*
94. **Tehran**, Iran, October 12–13, 2013; Organizer: *Nima Rezaei*
95. **Ptuj**, Slovenia, October 18–19, 2013; Organizer: *Tadej Avcin*
96. **Krasnoyarsk**, Siberia, Russia, October 22, 2013; Organizer: *Irina Tuzankina*
97. **Malatya**, Turkey, November 16, 2013; Organizer: *Ismail Reisli*
98. **Budapest**, Hungary, November 22, 2013; Organizer: *László Maródi*
99. **Pushkin Hills**, Russia, February 5, 2014; Organizer: *Areg Totolian, Marina Guseva*
100. **Antalya**, Turkey, March 12–14, 2014; Organizer: *László Maródi, Ismail Reisli*
101. **Antalya**, Turkey, March 15 2014; Organizer: *Ismail Reisli*
102. **Zagazig**, Egypt, April 17, 2014; Organizer: *Mohamed Almaky*
103. **Tehran**, Iran April 22–29, 2014; Organizer: *Nima Rezaei, Asghar Aghamohammadi*
104. **Poltava**, Ukraine, April 24–25, 2014; Organizer: *Liudmyla Chernyshova*
105. **Bratislava**, Slovakia, April 25, 2014; Organizer: *Peter Ciznar*
106. **Debrecen**, Hungary April 26, 2014; Organizer: *László Maródi*
107. **St. Petersburg**, Russia, May 28, 2014; Organizer: *Tatiana Nasyrina*
108. **Varna**, Bulgaria, October 6, 2014; Organizer: *Elissaveta Naumova*
109. **Catez**, Slovenia, October 11–12, 2014; Organizer: *Tadej Avčin*
110. **Tehran**, Iran, October 18–19, 2014; Organizer: *Nima Rezaei*
111. **Yekaterinburg**, Russia, October 24–25, 2014; Organizer: *Irina Tuzankina*
112. **Warsaw**, Poland, October 24–25, 2014; Organizer: *Ewa Bernatowska*
113. **Pardubice**, Czech Republic, November 11, 2014; Organizer: *Anna Sediva*
114. **Nizhny Novgorod**, Russia, November 26, 2014; Organizer: *Tatiana Nasyrina*
115. **Sibiu**, Romania, November 27–28, 2014; Organizer: *Sorin Iurian*
116. **Erzurum**, December 6, 2014; Organizer: *Dilara Kocacık Uygün, Demet Hafizoğlu*
117. **Chisinau**, Moldova, December 12, 2014; Organizer: *Liudmila Cerempei*
118. **Moscow**, Russia, February 18–19, 2015; Organizer: *Irina Kondratenko*
119. **Budapest**, Hungary – JPSC, March 5–6, 2015; Organizer: *László Maródi*
120. **Bratislava**, Slovakia, April 21–22, 2015; Organizer: *Peter Ciznar*
121. **Minsk**, Belarus, April 23–24, 2015; Organizer: *Mikhail Belevtsev*
122. **Debrecen**, Hungary, April 25–26, 2015; Organizer: *László Maródi*
123. **Tehran**, Iran, April 22–23, 2015; Organizer: *Nima Rezaei*
124. **Antalya**, Turkey, April 29, 2015; Organizer: *Ismail Reisli*
125. **Orel**, Russia, May 14–15, 2015; Organizer: *Irina Snimshehikova*
126. **Sakarya**, Turkey, May 17, 2015; Organizer: *Ismail Reisli*
127. **Zhytomyr**, Ukraine, May 21–22, 2015; Organizer: *Liudmyla Chernyshova*



128. **Ljubljana**, Slovenia, May 22–23, 2015; Organizer: *Tadey Avcin*  
129. **St. Petersburg**, Russia, June 3–4, 2015; Organizer: *Marina Guseva*  
130. **Perm**, Russia, July 2–3, 2015; Organizer: *Irina Tuzankina*  
131. **Timisoara**, Romania, Sept 3–4, 2015; Organizer: *Margit Serban*  
132. **Tehran**, Iran, October 8–9, 2015; Organizer: *Nima Rezaei*  
133. **Tirana**, Albania, November 20–21, 2015; Organizer: *Georgina Kuli-Lito*  
134. **Bořetice**, Czech Republic, November 19–20, 2015; Organizer: *Anna Sediva*  
135. **Plovdiv**, Bulgaria, November 20, 2015; Organizer: *Marianna Murdjeva*

**2014**  
**J PROJECT CONGRESS**  
**Antalya, Turkey**

1st	J Project Congress
10th	Anniversary of the J Project
100th	J Project Meeting
1000th	Gene sequencing in Debrecen



## THE J PROJECT

### Steering Committee Members

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3. Belarus	Minsk	<b>Mikhail Belevtsev</b> belevtsev_m@mail.ru
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## Links

### **The J Project (JP)**

*<http://jprojectnetwork.org>*

### **Jeffrey Modell Foundation (JMF)**

*<http://www.info4pi.org>*

### **International Patient Organisation for Primary Immunodeficiencies (IPOPI)**

*[www.ipopi.org](http://www.ipopi.org)*

### **Immune Deficiency Foundation**

*<http://primaryimmune.org>*

### **International Nursing Group for Immunodeficiencies (INGID)**

*<http://www.ingid.org>*

### **European Society for Immunodeficiencies (ESID)**

*<http://www.esid.org>*

### **Clinical Immunology Society (CIS)**

*<http://www.clinimmsoc.org>*

### **Latin American Society for Immunodeficiencies (LASID)**

*<http://www.lasid.org>*

### **African Society for Immunodeficiencies (ASID)**

*<http://www.asid.ma>*

### **Asia Pacific Society for Immunodeficiencies (APSID)**

*<http://???>*

### **International Union of Immunological Societies (IUIS)**

*<http://www.iuisonline.org>*

### **Federation of Clinical Immunology Societies (FOCIS)**

*<http://www.focisnet.org>*

### **European Federation of Immunological Societies (EFIS)**

*<http://www.efis.org>*

### **American Academy of Allergy & Asthma and Immunology (AAAAI)**

*<http://www.aaaai.org>*





## THE TAKEOVER OF THE DEPARTMENT OF INFECTIOUS AND PEDIATRIC IMMUNOLOGY

At the suggestion of the rector of the University of Debrecen, the Department was suddenly and unexpectedly closed down in November, 2015. The Laboratory that served as a JMF Laboratory, supporting the functioning of the J Project was also subsequently closed, and its equipment, including the ABI 3010 sequencer, the flow cytometer, freezers and hoods and the laboratory staff were taken over by the Laboratory Medicine Institute. The Department's buildings were taken over by the Department of Pediatrics, under the direction of the medical director of the Clinical Center, who is also the head of the Pediatric Department. All the arguments put forward by the most prominent leaders of the local and international PID community against this brutal assault on PID patient care and diagnosis in Central and Eastern Europe have fallen on deaf ears. Sadly, this unfortunate event extends well beyond the Debrecen center, as **any damage to any PID center anywhere in the world hurts the whole closely associated PID community.** It remains a mystery and to be defined how such unprofessional decisions can be made in such an authoritarian way by leaders of a European university without discussion, consultation, and consensus with professionals. Such a practice strongly resembles the dark era of Hungary in the fifties when people in quilted coat occupied and took over properties of honest citizens on behalf of the communistic party. We believe that this era will not return to our country but if yes, it will be eradicated soon. We also hope that our nationally and internationally recognized Department with a complex clinical, educational and research activity and international networking program will very soon be restored in its original structure and function for the benefit of patients with PID and infectious diseases. The temporary translocation of the JMF center and the J Project to a European or USA university is in progress.



*László Maródi*

*Melinda Erdős*

**Aranyosi Ervin:**  
**A DEBRECENI HŐSÖKNEK**

.....  
*Új remények várnak , higgy hát bennük kérlek,  
A hit csodás gyógyszer, így gyógyul a lélek.  
Legyőzhetsz Te bárkit, nincs mitől félni,  
Akarj szeretetben, boldogságban élni!*

*Kívánok hát erőt, ami meg van benned,  
Vágyat, hogy repítsen, teljessé kell lenned!  
Gyógyulj, erre kérlek, jó gyorsan és szépen  
S mosolyod ragyogjon szájad szegletében!*

**Ervin Aranyosi:**  
**TO THE DEBRECEN HEROS**

.....  
*New hopes are waiting and you need to believe,  
Live faithfully and your soul will be healed.  
You must overcome and never be afraid,  
Live in love and happiness,  
the only reward there is.*

*I wish you to be always strong and brave,  
Building hopes to fly and remaining safe.  
When you are ill I hope you get well fast,  
The smile on your lips should never last.*

(Translated from Hungarian by László Maródi)





*Debrecen, 2015*



*Budapest, 2015*