THE J PROJECT

EDITORS:
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with the contribution of
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Melinda Erdős, Maria Guseva, Irina Kondratenko, Georgina Kuli-Lito,
Noémi Miltner, Marianna Murdjeva, Elissaveta Naumova, Ismail Reisli,
Nima Rezaei, Anna Sediva, Margit Serban, Svetlana Sharapova,
Irina Snimshchikova, Areg Totolyan, Irina Tuzankina

March, 2016
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.

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

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

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 lections we had very good dialog and discussion with our colleagues (Diagnost 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.
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

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)
Bratislava, Slovakia

April 22

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. (Vieden)

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., Bánovčin P. (Martin)

Diagnostic and therapeutic approach in chronic enteropathy in patients with CVID – Case report
Raffač Š. (Košice)

First cases of Familial Mediterranean Fever in Slovakia

Dallos T., Lukáčiková Gálová L., Maciejková E., Ilenčiková 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
Hrubiško M., Kayserová H., Kossarrová K., Horáková J., Brezina M., Pružinec P. (Bratislava)

Conclusion remarks
Social event

Peter Čižnár
MINSK, BELARUS

Hosts: Mikhail Belevtsev (belevtsev_m@mail.ru)

Venue: Hotel Belarus

PROGRAM

Plenary session 1

Immunodysregulation in PID_part 1
(lymphoproliferation, autoimmunity)
Moderators: Nima Rezaei, 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 Institute; 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. Yeltsin
11.20–11.35 Activated phosphoinositide 3-kinase δ-syndrome. Analysis of 7 cases
Inga S. Sakovich, S. Sharapova, PhD, Belarus, Minsk
Belarusian Center for Pediatric Oncology, Hematology and Immunology
11.35–12.00 Autoimmune disease in children with primary immunodeficiencies
Irina N. Smirnova, MD, Russia, Moscow
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 lymphoproliferation in children
Svetlana Sharapova, PhD, Belarus, Minsk
Belarusian Center for Pediatric Oncology, Hematology and Immunology

Plenary session 2

Immunodysregulation in PID_part 2
(bowel diseases and neurological problems) and PID Registries
Moderators: Anastasia V. Bondarenko, MD, PhD, Svetlana Sharapova, PhD
12.30–12.45 Inflammatory bowel disease – is it primary defect of innate immunity?
Natalia Kalinina, MD, PhD, professor, Russia, St-Petersburg
All-Russian Center of Emergency and Radiation Medicine of A. Nikiforov Russian Emergency Situations Ministry
12.45–13.20 Homozygous mucosa-associated lymphoid tissue (MALT1) mutation in two siblings with immunodeficiency and chronic enteropathy
Gasper Markelj, MD, PhD, Slovenia, Ljubljana
Department of Allergology, Rheumatology and Clinical Immunology University Medical Centre Ljubljana
13.20–13.35 Brain immunology
Viktorija Kenina MD, PhD, Latvia, Riga
Plenary session 3
New technologies in PID diagnostics and Hereditary Angioedema
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 National PID Registry (Belevtsev M., Aleshkevich S.), new form of PID such as APDS (Sharapova S.) and results of transplantation PID patients (Aleinkova O.).

M. Belevtsev and S. Sharapova

M. Belevtsev and S. Sharapova

L→R: N. Rezaei and O. Aleinkova

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

O. Aleinkova opening the Conference

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

M. Belevtsev (L) and S. Sharapova (R) presenting their talks
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 PID 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 Tiszta István Hospital, Berettyóújfalu
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, Góncziné 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 Szekecz: 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.

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

Meeting of parents and doctors
TEHRAN, IRAN

Hosts: Nima Rezaei (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.

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 Heath 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
**ANTALYA, TURKEY**

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

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**PROGRAM**

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

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**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*
OREL, RUSSIA

May 14–15

Hosts: Irina Snimshchikova (snimshikova@mail.ru)
Venue: The Medical Institute of Orel State University

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:**

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 postgraduate 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 hypodiagnostics, 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
**SAKARYA, TURKEY**

**May 17**

**Host:** Ismail Reisli (ireisli@hotmail.com)

**Venue:** NG Sapanca Otel

**Main topic:** From laboratory testing to the diagnosis of PID

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**PROGRAM**

13.00–14.00 Öğle yemeği (Lunch)

Başkan: Prof. Dr. Yıldız Camcıoğlu, İsmail Reisli

14.00–14.20 Lenfopeni

Prof. Dr. Yıldız Camcıoğlu

14.20–14.40 Hipogammaglobulinemi, Hipokomplementemi

Prof. Dr. İsmail Reisli

14.40–15.00 Nötropeni

Prof. Dr. Mustafa Yılmaz

15.00–15.30 Discussion

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**SUMMARY**

We had organized a J Project Meeting in Sakarya during a Pediatric Asthma Meeting to increase 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 three Turkish 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 ambiance 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_

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

*Sight-seeing tour to the Sapanca Forest*
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. Lapit (Kiev, Ukraine), Y.S. Stepanovskiy (Kiev, Ukraine), Y. Romanyshyn (Lviv, Ukraine), H.M. Hilzanova (Kiev, Ukraine), I. Savchak (Lviv, Ukraine), S.A. Yakymovych (Kiev, Ukraine), I.A. Hladun (Zhytomyr, Ukraine), T.V. Oska (Mykolaiv, Ukraine), I.S. Sycheva (Dnipropetrovsk, Ukraine), H.S. Benko (Ivano-Frankivsk, Ukraine), O.V. Stynch (Mukachevo, Ukraine), L.D. Nikonets (Chernihiv, Ukraine), I.F. Kimlyk (Cherkasy, Ukraine), L.I. Nazarenko (Cherkasy, Ukraine), O.I. Malko (Rivne, Ukraine), N.E. Hryniyova (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 (Khmelnytskii, 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”
15.00–15.20 A.P. Volokha (Kiev, Ukraine) Syndromic Hypogamma-globulinemia
15.20–15.40 N.I. Vasylenko (Kherson, Ukraine) Wiskott-Aldrich Syndrome Autoimmune Manifestations, Treatment Problems
15.40–16.00 S.O. Sharapova (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. Hryniova (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 “Radomysl” 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
LJUBLJANA, SLOVENIA

May 21–22

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 Derviševič
- Children with immune diseases – Psychological aspects of chronic illness
  Mateja Gorenc
- A report from meeting of National societies of patients with rheumatic diseases
  Mirjam Kepic
- 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
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 Totolian
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, Belarus)
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-
emia in children: 34 year experience of a single center
Małgorzata Pac (Poland)
15.30 Genealogical analysis of primary immunodeficiency in adult patients
Karakina M., Tuzankiina I. A. Sher-shnev V.N. (Ekaterinburg, Russia)
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.

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

Vladimir I. Ioffe
(1898–1974)

Areg Totolyan
**PERM, RUSSIA**

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

**Venue:** House of Diaghilev

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**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)*

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**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 entrepreniser, 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 microorgan...
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 biding (UL) and interior of the House of Diaghilev (venue of the J Project Meeting)
Conference in House of Diaghilev

Elena Vlasova
Valeriy Chereshnev, Ivan Kozlov, Andrei Prodeus

Valeriy Chereshnev, Irina Tuzankina
Svetlana Zamorina, Juliya Ziyatdinova
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, Şerban 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?
Şerban M., Bataneant M., Baica M. (Timisoara)
Symptomatic selective IgA deficiency in children
Rugină A., Alexoae M., Ioniuc I., Petruţ 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., Pascalau 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.1, 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., Moroşanu 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  

Autoimmune encephalitis – a possible face of a PID  
_Popa C., Bacos C., Badeti R., Izverniaru 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
TEHRAN, IRAN

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
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 Ferdowski’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.

Nima Rezaei

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

BOŘETICE, CZECH REPUBLIC

November 19–20

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 immunodeiciencies
   chairs: Anna Šedivá, Tomáš Freiberger, Jiří Litzman
Hummoral immunodeficiencies. (20 min.)
   Pavlína 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 Formáňková
Stem cell transplant in PIDs. (20 min.)
   Tomáš Kalina
EuroFlow PID. (20 min.)
   Tomáš Freiberger
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 satelite 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 Project meeting

View of Bořetice, Moravia

View of Bořetice
HOST: Marianna Murdjeva (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.
TIRANA, ALBANIA  

November 20–21

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 Veveçka

14.00–14.20 Immunodeficiencies and the rheumatic diseases  
Gent Xhelili

14.20–15.00 A case with congenital neutropenia and extrahematopoetic multisystemic manifestations”-case report  
Sonila Borići

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
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 Ellenes
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. Zaporozhye, 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
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
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. Diyarbakır, 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 Batameant
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 Avčin
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 Avčin
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 Kocak Uygur, Demet Hafizoğlu
117. Chisinau, Moldova, December 12, 2014; Organizer: Liudmila Cerempeii
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 Avčin
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

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**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
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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

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)