THE J PROJECT

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March 2018
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For further details: www.jprojectnetwork.com

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Based on established traditions the story of the J Project in 2017 is told in separate reports following the chronological order of physician education meetings. Year by year we receive varying style reports that may represent one of the many colours of the J Project. These reports give different level of information. Importantly, however, the original guidance on aims of J Project meetings is still valid (see J Project Booklets 2004–2013) and reports in our precious Booklets should be proportionate with these aims regarding both forms and contents.

It is critically important how the existing diagnostic and treatment problems are managed as a result of the J Project meetings in the given region or country. The number of diagnosed and treated PID patients sensitively shows the impact of the JP meetings and the level of local professional activity. Over the past decade we have seen more and more doctors from JP countries attending international meetings organized for example by ESID, CIS, JMF and pharmaceutical companies and I strongly believed that overlapping and intervening PID education meetings are highly beneficial to increase global knowledge in the field. These meetings make sense if they translate into an increasing number of diagnosed PID patients.

The J Project has always been country-focused and continent-oriented. Particular attention has been given to establish and further develop existing communication between professionals, health care leaders, and patients. A stronger collaboration between JP countries in the field of molecular testing is also needed. The majority of JP countries are still hanging on centers in Western European countries and the USA for WES or WGS analysis or even Sanger sequencing. Good examples should also be mentioned, however, like the genetic diagnostic help provided by the Minsk Center to countries in Central-Asia and Ukraine.

It was clear from the beginning that the development of PID patient care would be unequal in various JP Countries because of differences in socio-economic conditions and financial resources of health care. In the 26 member countries the prevalence of PID in the general population varies remarkably. This implies that the target of the J Project programs should be differentiated. The challenges are still enormous in most JP countries despite our efforts over the past decade. Cessation of IVIG treatment in Romania, an EU member country, for more than a year, i.m. immunoglobulin replacement in adult XLA patients in Moldova because they never registered IVIG or SCIG preparations, no diagnosed PID patients in Uzbekistan with a population of 30 million, or the brutal demolition of the PID center and genetics laboratory in Debrecen are just a few examples. The increasing difficulties our colleagues are facing in diagnosis and treatment of PID patients on Bosnia and Herzegovina, Macedonia, Moldova, Kosovo, Egypt, Central Asia and elsewhere add to the ongoing responsibility of the J Project to help to manage or at least ameliorate these problems and to promote advanced PID care in more developed countries in Central and Eastern Europe and elsewhere.

New York, March 15, 2018

László Maródi
## Meetings in 2017

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In his introduction, László Maródi outlined the structure of the J Project emphasizing the role of the SC in decision making. Each member country have a minimum of one seat in the SC. The Executive Committee established at the 2016 J Project Congress in Antalya serves as an operative body and the Foundation for Children with Immuno-deficiencies based in Hungary is responsible for running the Project. The list, dates and venues of the SC Meetings and the first EC meeting are shown at the end of this Booklet. We also listed the members of the JP Executive Committee.

Ambassadors accredited to Budapest from J Project countries as well as representatives of the Hungarian Government were invited to the 2017 JP SC Meeting. The following core information was disseminated to help them understand the concept and achievements of the Project:

“The J Project is a physician education and clinical research collaboration program started in 2004 in Hungary and extended later to the whole area of Central and
Eastern Europe and part of Asia and Africa (www.jprojectnetwork.com). Over the past decade the J Project has established itself as a successful prototype for awareness programs for primary immunodeficiency diseases (PIDs) and until now 26 countries joined. There were 149 physician education meetings that have been organized and in 2014 the Project culminated in a J Project Congress in Antalya, Turkey with hundreds of participants. A Declaration by the participants was approved. The next J Project Congress was organized in 2016. The J Project is led by the Steering Committee and Executive Committee. Since 2010 Steering Committee Meetings have been organized, mostly in Budapest each year in order to make strategic plans by leading experts from J Project Countries. This year the SC meeting will also take place in Budapest and for the first time, the SC decided to invite Ambassadors accredited to Hungary from J Project countries. The purpose of this invitation is to introduce the J Project to diplomatic representatives of the particular countries and to ask their help to promote the progression of the Project in their own countries.

Delegates from a few embassies attended the first session of the SC Meeting and the Government of Hungary was represented by Dr. István Mikola. On March 1, László Maródi gave a short overview on the J Project followed by a scientific presentation by András Falus, professor of immunology and genetics at Semmelweis University in Budapest. Dr. Falus focused on recent developments and future challenges of genetic diagnostics of human genetic diseases, a topic which is particularly relevant to those taking care of patients with primary immunodeficiency disorders. István Mikola, an infectious diseases expert by profession and currently Minister of State for Security Policy and International Cooperation at the Hungarian Ministry of Foreign Affairs and Trade gave an overview on international collaborative programs coordinated by his Department and focused on health care and disease prevention in developing countries. The concept of this presentation was to accommodate better the J Project as a physician education and clinical research collaboration program among other existing projects in the J Project area. On March 2, the discussion followed on relevant professional issues of the J Project programs and plans for the year 2017.

László Maródi
Participants of the 8th SC Meeting:
KONYA, TURKEY
April 17, 2017

Host: Ismail Reisli
Venue: Meram Medical School, Conference Room, Konya
Main Topic: Diagnosis and Treatment of Primary Immunodeficiency

PROGRAM

SUMMARY

We organized a J Project Meeting in Konya, Turkey, on April 17, 2017, to increase awareness of primary immunodeficiency (PID) diseases among physicians and medical students. The main topic of Konya Meeting was “Diagnosis and treatment of Primary Immunodeficiency”, and Prof Talal Chatila joined us.

Konya J Project Meeting was organized with Necmettin Erbakan University and Harvard University, and was primarily focused on the awareness, clinical signs and treatment of PIDs among the physicians (especially pediatricians) and medical students. The importance of early diagnosis in patients with PIDs was also discussed. There were 100 participants attein attendance. Prof Talal Chatila gave his lecture about the immune dysregulation. During the discussion, participants spoke about the importance of early diagnosis and early treatment of the pediatric and adult patients with PID.

I would like to thank all participants and speakers for their contribution to Konya J Project Meeting.

Ismail Reisli
**TEHRAN, IRAN**  
April 21–22, 2017

**Hosts:** Nima Rezaei & Asghar Aghamohammadi  
**Venue:** Research Center for Immunodeficiencies, Children’s Medical Center Tehran University of Medical Science, Tehran  
**Main Topic:** Approach to Primary Immunodeficiencies

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**PROGRAM**

**April 21**

**Opening Session**
President of RCID and ICID Conference  
A Aghamohammadi  
Deputy President of ICID and Chair of Scientific Committee of ICID  
N Rezaei  
Keynote lecture: Inborn errors of immunity and susceptibility to fungal diseases  
*A Puel (Paris)*

**Session 2**

**Head and neck manifestation of Primary Immunodeficiencies (PIDs)**
Approach to patients with abnormal facies and recurrent infection  
*M Safari*  
Approach to patients with partial albinism and recurrent infection  
*MH Bemanian*  
Approach to patients with lymphoid atrophy and lymphoproliferation associated recurrent infection  
*F Zandieh*  
Approach to patients with recurrent meningitis and HSV encephalitis recurrent infection  
*J Ghaffari*

**Session 3**

**Essential approach to Primary Immunodeficiencies**
Approach to patients with antibody deficiency  
*A Aghamohammadi*  
Approach to patients with cellular immunodeficiency  
*Z Chavoshzadeh*  
Approach to patients with T-cell function defect  
*M Mesdaghinia*  
Approach to patients with phagocytosis defect  
*N Rezaei*  
Approach to patients with complement defect  
*I Mohammadzadeh*  
Approach to patients with complement defect  
*H Abolhassani*

**Session 4**

**Poster Presentation**

**Session 5**

**National PID network**
Report of Performed activities  
Steering committee voting  
Future plan and perspective  
*A Aghamohammadi, N Rezaei*

**April 22**

**Session 6**

**Presentation of interesting cases**
Keynote lecture: NGS in diagnosis of PID  
*G Romeo (Italy)*
Session 7
Respiratory and dermatologic manifestation of Primary Immunodeficiencies
Approach to patients with recurrent sinusitis
A Ahmadi Afshar
Approach to patients with recurrent pneumonia
A Shafiee
Approach to patients with opportunistic pneumonia
F Jabbari
Approach to patients with bronchiectasis
M Tavakol
Approach to patients with Granulomatosis
S Aleyasin
Approach to patients with Angioedema
T Cheraghii
Approach to patients with Skin infections
M Nabavi

Session 8 Side effects of attenuated vaccines and specific infections in Primary Immunodeficiencies
Approach to patients with generalized warts
M Khoshkhoei
Approach to patients with cutaneous candidiasis
N Parnavaneh
Approach to patients with Vaccine-associated paralytic polio
HR Mortazavi
Approach to patients with MMR vaccine side effects
MH Eslamian
Approach to patients with BCG adenitis
A Mahdaviani
Approach to patients with deep abscess
H Ahanchian

Session 9
Poster Presentation

Session 10
Laboratory findings hints for Primary Immunodeficiencies
Approach to patients with neutropenia and recurrent infection
M Sadeghi Shabestari
Approach to patients with lymphopenia and recurrent infection
M Heydarzadeh
Flow cytometry application in PID: R Yazdani
Approach to patients with ITP and recurrent infection
T Momen
Approach to patients with AIHA and recurrent infection
R Nasiri
Concluding remarks
SUMMARY

The 9th Meeting on Clinical Immunology and Immunodeficiencies, also recognized as a J Project Meeting, was organized on April 21–23, 2017 in Tehran.

In 2005, the First International Congress on Immunodeficiency Disorders was organized in Tehran. A number of PID experts from different countries (USA, UK, Germany, France, Italy, Sweden, Spain, Japan, and Turkey) attended the Congress. They presented updates in this field, and there was a remarkable participation of scientists and researchers who took part in this Congress to learn about the progress in the field. This congress was a great event to further develop bilateral scientific exchange of Iranian scientists with other researchers around the world.

In October 2009, alongside the 21st International Congress of Pediatrics, a joint meeting on Immunodeficiency Diseases was held. The two day meeting was supported by the Jeffrey Modell Foundation.

The huge success of these conferences raised the idea of organizing the Clinical Immunology, Allergy and Immunodeficiency Diseases Meeting this year, just before the 22nd International Congress of Pediatrics. This meeting, which was considered the 153rd J Project Meeting, was organized by the Research Group for Immunodeficiencies in collaboration with the Department of Pediatrics of the Children’s Medical Center Hospital, Tehran University of Medical Sciences.

Since 2011, since the establishment of the Research Center for Immuno-deficiencies, the Meetings on Clinical Immunology and Immunodeficiencies is organized annually along with the International Congress of Pediatrics in October.

This year, the meeting was organized separately again in April by the Research Center for Immuno-deficiencies as the 9th Conference of Immunodeficiency Diseases. Improving the awareness of physicians, pediatricians and other specialists was the main objective. We were very pleased to host over 500 delegates who attended this year. The majority of the audience included general practitioners, pediatricians, and pediatric subspecialists; however, medical students, pediatric residents and fellows in the field of clinical immunology and infectious diseases have been actively participated in the meeting.

The meeting was organized in 10 sessions, and there was a 2nd PID school on April 23, organized by the Universal Scientific Education and Research Network (USERN), supported by the European School of Genetic Medicine (ESGM). There was also a celebration of PI Week, organized by the Health and Art (HEART) group, where the speakers along with the kids met in the park and visited painting galleries.

Nima Rezaei
**KAUNAS, LITHUANIA**

| Host: | Brigita Sitkauskiene |
| Venue: | Auditorium 42, Department of Immunology and Allergology, Lithuanian University of Health Sciences, Kaunas |
| Main Topic: | Current and future perspectives on PID patients care |

**PROGRAM**

**April 26**

Introduction

Present and future perspectives of the Kaunas Primary Immunodeficiency Center

*B Sitkauskiene*

Diagnostic possibilities in immunodeficiency

*M Paulauskiene, I Peciuliene*

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Signs and treatment standards of congenital angioedema

*J Staikuniene*

Supporting self-care for patients and their families

*M Jusinskaite*

Interactive discussion

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*Soup bubbles and alchemic performances*
SUMMARY

This J Project Meeting was organized by the Center of Primary Immunodefiency, the Hospital of Lithuanian University of Health Sciences, the Lithuanian Society of Allergology and Clinical Immunology, and the Jeffrey Modell Foundation.

Every April, along with many people around the world, we celebrate World Primary Immunodeficiency Week. The main aim of this event is to raise awareness about PID diseases. This year, the Center of Primary Immunodeficiency, Lithuanian University of Health Sciences Kauno Klinikos, led by Brigita Sitkauskiene, invited everyone who is interested in primary immunodeficiencies – physicians, biologists, patients and their family members - for a close discussion about these rare diseases.

The meeting opened with a short overview of the newly established Department of Immunology and Allergology where the Center of Primary Immunodeficiency is located. The leader of the Center, Brigita Sitkauskiene gave an introduction of activities of the Department and the Center. Patients of all age groups with suspected immunodeficiency can be offered consultation at the Center. Management of these patients is based primarily on the newest guidelines for various congenital immune deﬁciencies. Specialists working in the Center supervise over 70 patients with various forms of primary immuno-deﬁciencies, and this number is increasing every year. The brief tour of the Immunology Lab was a good experience for meeting participants, who had never seen how the diagnostic laboratory tests are done.

During the meeting, various topics were discussed. J. Staikuniene gave a talk about hereditary angioedema. Other specialists of allergology and clinical immunology made some important points about the diagnostics and genetic counseling of subjects with suspected primary immunodeficiency. An invited psychologist drew attention to the importance of psychological care and self-care, offering some practical recommendations for patients who have life-lasting diseases.

Even though individual primary immunodeficiencies may be rare conditions, patient should not feel alone. Medical professionals try to rally them together, so they...
could share their experiences, as well as encourage them to participate in other organizations for patients with rare diseases. As primary immunodeficiency might become a serious challenge for a doctor, the patient and his/her family, we emphasize the importance of close communication and trust.

At the conclusion of the event, with the aim to promote a positive sentiment, experiments with soup bubbles and alchemic performances were made. We all had a wonderful and memorable time.

Brigita Sitkauskiene
 PROGRAM

9.30 Hyper-IgM syndróm
10.00 Od symptómu k syndrómu
10.20 Nová terapeutická nádej pre pacienta s X-viazanou trombocytopéniiou
10.40 DiGeorge syndróm a autoimunita
11.00 e-Health na Slovensku
11.30 PID from adult perspective – Manchester experience
12.00 Organizácia starostlivosti o PID pacientov
12.20 Idiopatická CD4+ lymfopénia
12.40 Gastrointestinalné komplikácie bežnej variabilnej imunodeficiencie
13.00 Těžká kombinovaná imunodeficiencie s atypickým průběhem
13.20 Hereditárna neutropénia – kazistika
14.30 Pokroky v terapii PID
14.30 Hematopoetic stem cell transplantsations in PID
15.00 Génová terapia primárnych imunodeficiencii
15.20 Aktivační mutace PI3-kinázy
15.50 Biologická liečba autoinflamatórnych chorôb
16.10 Advanced immunoglobulin therapy in Germany
16.30 Záverečné slovo
ESKİŞEHİR, TURKEY

May 5, 2017

Host: Ismail Reisli
Venue: Osman Gazi Medical School Conference Room, Eskişehir
Main Topic: Diagnostic clues for primary immunodeficiency

PROGRAM

SUMMARY

We had organized a J Project Meeting in Eskişehir to increase the awareness of primary immunodeficiency (PID) diseases among the pediatricians and medical students in Osman Gazi University. The main topic of the Eskişehir Meeting was “Diagnostic clues for Primary Immunodeficiency”, and there was a panel of two Turkish lecturers.

Eskişehir J Project Meeting was held on May 5, 2017 in Turkey. The meeting was organized at Osman Gazi University and was primarily focused on the awareness, clinical signs and treatment of PIDs among the physicians (especially pediatricians) and medical students. There was also a discussion about the importance of early diagnosis in the patients with PIDs.

The meeting was attended by 50 participants. During the discussion, the participants spoke about the importance of early diagnosis and early treatment of the pediatric and adult patients with PIDs.

I would like to thank all the participants and speakers for their contribution for Eskişehir J Project Meeting.

Ismail Reisli
The Fairy Tale Castle

River Porsuk
Program

A report from the International Patient Organisation for Primary Immunodeficiencies – IPOPI, JMF and National society of patients with PID
Štefan Blazina (Ljubljana)

A report from the meeting of the European network for children with arthritis – ENCA
Mirjam Kepic (Ljubljana)

Physical activity of children with PID (recommended sport activity, school gym classes, etc.)
Gašper Markelj (Ljubljana)

Recommendations for travelling with medications for patients treated with subcutaneous Ig (airplane, car, ship, camping, etc.)
Maja Čamernik (Ljubljana)

A report from the International Ataxia-Telangiectasia workshop in Milan, March 2017
Lana Dakić

Summary

Traditional meeting for children with immune diseases and their parents was held on 13th May 2017 in Ljubljana, Slovenia (organized by the Slovenian association for children with immune diseases). Scientific program was focused on physical activity of
patients with PID, travelling with medications, new advances in the field of Ataxia-Telangiectasia, and reports from ENCA, IPOPI and National society of patients with PID.

Social program was organized for children during the lectures. This year we were visited by the House of Experiments from Ljubljana, whose mission is to make people excited about learning. The children had the opportunity to explore some 46 experiments while learning and testing their knowledge. During buffet lunch, parents and health care workers had an opportunity to discuss different aspects of disease and share ideas for future.

*Tadej Avcin*
On May 18–19, 2017, the 13th Ukrainian scientific and practical symposium entitled “Primary immune deficiencies in practice of pediatricians and family doctors: The XIII Ukrainian J Project Meeting” took place in the city of Kropyvnytskyi (former Kirovohrad) with foreign participation.
under the “J Project” Central and Eastern European program. Earlier, similar symposia aimed to raise awareness of primary immune deficiencies were held in 12 regions of Ukraine: Kyiv (2004), Lviv (2005), Zaporizhzhia (2007), Odesa (2008), Sevastopol (2009), Kharkiv (2010), Lutsk (2011), Chernihiv (2012), Mukachevo (2013), Poltava (2014), Zhytomyr (2015), and Chernivtsi (2016). This event was promoted by the Kirovohrad Regional State Administration.

Pediatric immunologists and pediatric hematologists from all regions of Ukraine attended the symposium. The conference brought together a large audience of various doctors of the Kirovohrad region, mainly pediatricians, family doctors, pediatric infectologists, allergists, and epidemiologists. The symposium was opened by LI Cher-nyshova, the President of the Ukrainian Association of Pediatric Immunology. She gave an overview of the achievements and problems regarding primary immune deficiencies in Ukraine through early 2017.

In Ukraine, new cases of PIDs are diagnosed every year. In 2016, 83 new cases of severe PIDs were diagnosed. According to the national registry maintained at the Department of Pediatric Infectious Diseases and Pediatric Immunology of National Medical Academy for Post-Graduate Education, named after PL Shupyk, the number of identified PIDs in Ukraine is 840, but the total number of PIDs may be 10 times higher. About 80% of children with PIDs are not referred to pediatric immunologists or referred too late, when it is impossible to cure them. Primarily, this is due to low awareness about PIDs by primary care physicians to provide appropriate medical care to affected children. Therefore, there is a need for additional education among pediatricians, family doctors and other professionals to create awareness and vigilance about PID in Ukraine.

The symposium program was made up of two parts this year. The first part was held as a seminar for local doctors to promote dynamic communication. Master classes were held by LI Chernyshova (Kyiv), YS Stepanskyi (Kyiv), FI Lapit (Kyiv), and IY Savchak (Lviv). Group work enabled doctors to raise questions to presenters and discuss clinical manifestations of PIDs based on their own clinical experiences. The
issues of criteria for early diagnosis of congenital immune deficiencies at the stage of primary care for children and indications for mandatory referral to a pediatric immunologist were envisaged. This facilitates a wider detection of primary (innate) immune deficiencies and timely intervention of an adequate treatment that saves lives as well as provides adequate quality of life.

In the second part of the event, pediatric immunologists listened to Ukrainian leading experts’ reports on current immunological diseases in children. AP Volokha presented on herpes infection of type 6. Geneticists GD Teleheiev and M Dybkov (Institute of Molecular Biology and Genetics of National Academy of Sciences of Ukraine) shared their achievements in the development of genetic diagnosis of PIDs, as well as PID genetic diagnosis prospects in Ukraine. Furthermore, YS Stepanovskiy’s information on PFAPA-syndrome treatment provoked much interest. The Project RAPID (Ukrainian abbreviation of “Early diagnosis of primary immune deficiency”) of UAPI was revealed by SA Beglaryan. The report of the leading pediatric hematologist, SB Donska informed participants about new possibilities for bone marrow transplantation in Ukraine and abroad, which is often a basic radical treatment for patients with PIDs. The symposium was attended by A Tsytsenko, a representative of “Rare immune diseases” patient public organization, who presented on progress over the last year.

LI Chernyshova concluded the symposium by sharing the results of the work by pediatric immunologists, the prospects of provision of replacement therapy for adult patients, as well as cooperation with pediatric hematologists, and upcoming conferences on primary immune deficiencies. After the symposium, a meeting of the Public Organization “Ukrainian Association of Pediatric Immunology” members took place, and important resolutions were adopted.

At the end of the meeting, a tour around Kropyvnytskyi was organized for the participants of the school-seminar, during which doctors got acquainted with the history of the region, saw the first professional Ukrainian theater in the country, where Maria Zankovetska started her acting, and also visited the fortress of Saint Elizabeth.

Liudmyla Chernishova
BAKU, AZERBAIJAN
June 1, 2017

Host: Gulnara Nasrullayeva
Venue: Business Center Landmark III (Salo Hall)
Main Topic: Diagnostics of Primary Immunodeficiencies in Azerbaijan

PROGRAM

Opening
Welcome and Opening remarks
G Nasrullayeva, A Ayyubova
Success in the work of the Azerbaijan Society of PID
G Nasrullayeva
Identification of a new BLNK gene in a patient with agammaglobulinemia
Sh Ibrahimova
Hypersplenism and pancytopenia in a patient with CVID
N Guliyeva
Congenital auto-inflammatory syndrome associated with LRBA gene
V Mammadova

Clinical and immunological features of the Louis-Bar syndrome
K Abdulgadirova
Primary cellular type immunodeficiency, diagnosis and treatment
A Khalilova
Successful bone marrow transplantation in patient with SCID
Z Mammadova
Stem cell transplantation as the main method in treatment of SCID
T Panahova
All
Concluding remarks

Gulnara Nasrullayeva
## PROGRAM

### June 7

**Session I**

**Opening**

Ewa Bernatowska, László Maródi, Maciej Siedlar  
Innate genetic defects underlying fungal diseases in humans  
László Maródi  
Molecular diagnosis in PID patients  
Miriam van den Burg (Rotterdam)  
EuroFlow lecture on diagnosis of lymphoid PID  
Jacques JM van Dongen (Leiden)  
Discussion  
Immunoglobulin substitution therapy in CVID patients: Prague CHNIN-STRAP Czech non-international study with rapid-push administration of 20% subcutaneous immunoglobulin  
Anna Sediva (Prague)  
Facilitated SCIG- clinical trials and practical experience  
Nicolas Brodszki (Lund)

Primary immune deficiencies – principles of care  
Małgorzata Pac (Warsaw)  
20-years of experience in hematopoietic stem cell transplantation in primary immunodeficiencies in Poland (we received two different programs)  
Beata Wolska-Kuśnierz (Warsaw)

**Session II**

Session of the Society “Polish Working Group for Immunodeficiencies”  
Primary Immunodeficiencies – Polish Road Map  
Karina Jahzn-Różyk (Warsaw)  
Comprehensive activities to increase recognition of PID and access to immunoglobulin replacement therapy in Poland  
Ewa Bernatowska, Małgorzata Pac (Warsaw)
SUMMARY

The XVIth Congress of the Polish Society of Experimental and Clinical Immunology and the 5th Conference of the Polish Working Group for Primary Immunodeficiencies together with active participation of J Project Group was organized, on June 7–10, 2017 and drew 378 participants. The scientific programme of this event drew together the leading national and international experts who discussed breakthroughs in basic and clinical immunology.

Prof. László Maródi was awarded, by the decision of the Board of the Polish Society of Clinical and Experimental Immunology, with the Ludwik Hirszfeld medal for his outstanding contribution to the field of clinical immunology and the development of the J Project clinical research collaboration and physician education program in Central and Eastern Europe.

Prof. László Maródi is largely associated with the mechanism of host defense against bacteria and fungi studies, immunity of the human neonate and pathophysiology of primary immune-deficiencies. Prof. László Maródi has acted as founder and leader of the J Project (www.jprojectnetwork.org) since 2004. The J Project physician education and clinical research collaboration program was to establish as a means to search for PID patients in Eastern and Central Europe (ECE). The Project has spread and reached milestone successes in terms of the number of diagnosed and treated patients. He introduced modern immunological and molecular diagnosis in primary immune-deficiencies, and for years has provided genetic diagnosis for PID patients from ECE countries in Debrecen, and continue now in Budapest.

Prof. Ewa Bernatowska
HOSTS: Elissaveta Naumova, Mariana Murdjeva
VENUE: Rehabilitation Center of MU – Plovdiv – Tsigov Chark
MAIN TOPIC: Summer school for children with PIDs and their parents

PROGRAM

June 17
Welcome speech
  Mariana Murdjeva
Session 1
  Register for immune-mediated rare diseases
    Elisaveta Naumova
  Immune system and immune response - essence and functions
    Victoria Saraifian
Primary immunodeficiency and related infections in children
  Mariana Murdjeva
Necessary laboratory studies in children with primary immunodeficiency
  Nevena Gesheva
Vaccines and post-vaccination immune response in children with PID
  Maria Nikolova

Session 2
Subcutaneous Immunoglobulin Therapy in Children with Primary Immune Deficiency
  Maria Spassova
Psychological problems in parents and children with PID – how to overcome them.
  Viktor Zlatkov
Administration of intravenous and subcutaneous immunoglobulin in children with PID (practical guidelines)
  Alexander Stoimenov
Non-specific immunomodulation and hygienic-dietary regimen in children with immune deficiencies. Isoprinosine
  Snezhina Mihaylova
Quality of life for people with PID in Bulgaria – Consultations and discussions – patient questions/answers from doctors.
  Rev. Stoil Lazarov from the Association of Patients with PID

June 18
Meeting of the National Working Group on Primary Immune Deficiencies
SUMMARY

This year’s summer school on primary immune deficiencies focused on pediatric patients. The meeting was organized jointly by the Expert Center for PID at „Alexandrovska” University Hospital – Sofia, Jeffrey Modell Foundation Sofia, Medical University – Plovdiv, the J Project and the Bulgarian Association of Clinical Immunology. The program included informative scientific reports, organizational meeting of the National Working Group on Primary Immune Deficiencies and an interactive discussion between physicians, pediatric patients with their parents, as well as experts and a representative of the patient organization. The meeting had a truly national footprint. The primary goals of the summer school were to familiarize families with PIDs as well as proactively interact with patients, thus aiming to improve their quality of life.

Mariana Murjeva gave a welcome speech on the Global J Project. Elissaveta Naumova presented the stages of formation of the National PID Working Group and the Expert Centers in Sofia and Plovdiv, as well as the implementation of novel tests that increase the diagnostic value of immunological testing, therapeutic options for replacement therapy with immuno-globulins and C1-esterase inhibitor in an outpatient setting, that are fully reimbursed by the NHIF. Naumova outlined the excellent collaboration that has been achieved with the patients’ organization, National Center for Rare Diseases, Chimimport Pharma and Ewofarma. Murdjeva’s presentation focused on the basic concepts in the PID field: microbes and infections, infectious complications in PIDs, as well as antibiotic treatment of these infections. The program continued with an overview of the immune system and immune response for patients, given by Victoria Sarafian, followed by a presentation by Nevena Gesheva, focusing on the laboratory panel that is to be tested in potential patients with PIDs. The next presentation, given by Mr Zlatev (clinical psychologist) focused on the management of the psychological problems in the families of children with PIDs. Maria Spassova presented her own experience in the use of substitution therapy with subcutaneous immunoglobulin (SCIG) in children with primary humoral immune deficiency compared to intravenous replacement therapy (IVIG).

The children with PIDs and their parents were trained on the essential functions of immunity, infections accompanying PIDs, diet and disease prevention by Snezhina Mihaylova. Interactive training of patients on the main steps in the use of subcutane-
ous immunoglobulin was conducted by Alexander Stoimenov from Chimimport-pharma. The “Common difficulties in patients” educational process and suggestions to mitigate these were presented by Rev. Stoil Lazarov, chairman of the PID patients’ organization in Bulgaria. At the end of the program there was an interactive discussion with the parents.

Elissaveta Naumova

ACTIVITIES FOR CHILDREN WITH PIDS

Reverend Stoil Lazarov, Chair of the patients’ organization in Bulgaria
Elissaveta Naumova together with parents and children
**PROGRAM**

**August 27**  
**Session 1**  
Genetic bases of invasive and mucocutaneous fungal infections.  
*László Maródi*  
Primary immunodeficiencies: New about the old.  
*AY Scherbina (Moscow)*  
Genetic and immunological features of combined immunodeficiencies  
*MV Belevtsev (Minsk)*  
J Project in Urals.  
*IA Tuzankina (Ekaterinburg)*  
Primary immunodeficiencies – Solved and unsolved problems in Chelyabinsk  
*AY Pishchalnikov (Chelyabinsk)*  
Hereditary Angioedema: introduction of recommendations into clinical practice  
*EK Beltiukov (Ekaterinburg)*  
Defects of the number and/or function of phagocytes according to the PID register of Chelyabinsk region  
*TV Shilova (Chelyabinsk)*  
The choice of IVIG. New opportunities  
*AY Scherbina (Moscow)*  
Patients with HAE in PID register of Chelyabinsk region  
*NN Abramova (Chelyabinsk)*  
Experience of using intravenous immunoglobulins  
*EV Vlasova (Ekaterinburg)*  
Postmortem diagnostics of PID in Sverdlovsk Region  
*MA Bolkov (Ekaterinburg)*

Molecular genetic diagnosis of PID and TREC and KREC studies in Sverdlovsk region  
*SS Deryabina (Ekaterinburg)*  
Pathology of the oral cavity in patients with PID  
*MA Dolgikh (Ekaterinburg)*

**Session 2**  
Analysis of clinical cases in the Regional Children’s Clinical Hospital, Department of Allergology and Clinical Immunology
This meeting was organized by the Russian Scientific Society of Immunologists, the Ural Society of Immunologists, Allergists and Immuno-rehabilitationists, the Ural Federal University, and “J Project” the international educational project on primary immunodeficiencies. J Project in Chelyabinsk was held in the framework of the XIV Conference of Immunologist of Ural at August 27–29, 2017. The meeting was attended by 580 doctors and scientists from 15 regions of Russia (include Moscow, Saint-Petersburg, Yekaterinburg, Perm, Novosibirsk and others), and invited doctors and scientists from Hungary and Austria also joined.

Irina Tuzankina
MOMENTS OF THE MEETING...
AND THE AFTERPARTIES

Ksenia Abramovskih, medical student, and László Maródi

L–R: Alexander Pishchalnikov, Irina Tuzankina, László Maródi

Dancing beauties at the Gala dinner

NO ONE IS FORGOTTEN
NOTHING IS FORGOTTEN
WWII Memorial monument
in Chelyabinsk

L–R: László Maródi, Nadejda Shmagel, Andrey Simbircev, Narine Sarkisyan, Irina Tuzankina, Konstantin Shmagel, and Irina Nesterova
PROGRAM

Rare immune-mediated diseases in Bulgaria – the challenge continues
  Mariana Murdjeva, Marta Baleva

Molecular diagnostics and genetic screening of primary immune deficiencies
  Snezhina Mihaylova

Study of the signaling pathways of T- and B-cell activation in common variable immunodeficiency – sight to the pathogenesis of disease
  Nevena Gesheva

Firazyr (Icatibant) for treatment of hereditary angioedema
  Todorka Beleva-Popova

Ataxia telangiectasia – case report
  Petya Yankova

Homozygous MyD88 deficiency – case report and literature review
  Neofit Spasov
SUMMARY

The beautiful city of Plovdiv traditionally hosts Bulgarian National Conferences for Rare Diseases and Orphan Drugs in September. In 2017 8th National Conference for Rare Diseases and Orphan Drugs was jointly held with the 12th Balkan Congress of Human Genetics on September 8-10, 2017 at the Congress Centre of Grand Hotel Plovdiv. Bulgarian Association of clinical immunologists, Jeffrey Modell PID Expert Center – Sofia, together with the Medical University-Plovdiv in the context of J-project organized a session on 9th of September focused on rare immune-diseases including primary immune deficiencies (PID).

New opportunities for improved diagnosis, treatment and follow up of patients with PID were presented. Innovations and trends in personalized and genomic medicine in PID were discussed. The moderators Prof. Marianna Murdjeva and Prof. Marta Balleva made an overview of diagnostics and therapeutical achievements in rare—immune-mediated diseases in Bulgaria with an accent on new challenges in genomic medicine. The scientific program included: Molecular diagnostics and genetic screening approaches of primary immune deficiencies, study of the signaling pathways of T- and B-cell activation in common variable immunodeficiency, interesting case reports on ataxia-teleangiectasia and homozygous MyD88 deficiency, and opportunities to treat patients with Hereditary angioedema in Bulgaria by Firazyr (Icatibant). The lecturers were clinical immunologists and pediatricians from University hospitals and departments in Sofia and Plovdiv. The conference session was attended by 70 participants – medical doctors and scientists, PhD students, medical undergraduate students, PID patients and business partners from pharmaceutical companies.

This joint event was an excellent occasion for new, expanded contacts among immunologists, pediatricians and PID patients at regional and European level.

Elissaveta Naumova and Mariya Ivanovska and Gergana Lengerova

Mariya Ivanovska and Gergana Lengerova
PROGRAM

Welcome
   Katalin Vámos (Budapest)
JP Booklet 2016
JP Meetings 2017
New JP countries
CIS Meeting, Boston
Ludwik Hirszfeld medal
   László Maródi (Budapest)

3rd J Project Congress
   Katalin Vámos, László Maródi (Budapest)
ERN-RITA – J Project
   All
Foundation of a JP Society
   All

SUMMARY

ERN-RITA – J PROJECT
A new European Reference Network (ERN) program on Rare Immunodeficiency, autoimmune, and inflammatory and autoimmune/rheumatic diseases (RITA) was launched recently by EU to improve collaboration between disease centers and exchange knowledge in the field of inflammatory and autoimmune/rheumatic diseases and immunodeficiencies. In general, the ERN-RITA project is promising and confirms the commitments of the EU to ensure uniform access to diagnosis and treatment of PID in Eastern and Western European countries. Importantly, this concept is in full agreement with the Antalya Declaration approved at our J Project Congress in 2014. However, despite Eastern-Europe having been defined as the major focus of interest of ERN-RITA, the J Project was neither approached nor included at the beginning suggesting a possible bias and misconduction of this new program. Also, only two Central-European centers, one in Prague and one in Ljubljana, became members of the initial network project. To clarify possible misunderstandings and to put RITA on the right track of responsibility, an ERN-RITA – J Project meeting entitled “General ERN-RITA Workshop/J Project/Development of Eastern Europe” was organized as part of the ESID 2017 Congress in Edinburgh, on September 12. Important outcomes were as follows:
   – Setting up ERN-RITA is still in development.
– An “affiliated center” status in countries with no ERN-RITA center may be established.
– The J Project may be supported directly within EU by EU centers and indirect support may be provided for non-EU JP centers.
– ERNs may be extended in future and applications for member status may become possible

STEERING COMMITTEE MEETING
The 9th J Project Steering Committee meeting was also organized during the ESID 2017 Congress. The new J Project Booklet was introduced by L Marodi. The JP Meetings that had been organized and those scheduled for the rest of the year were reviewed. Armenia, Georgia and Uzbekistan were expected to be new JP Countries. L Marodi reported on the PID-focused program of the Clinical Immunology Society and about the activity of the Membership Committee in which the J Project has a seat. The achievements of the J Project and the successful long term collaboration between the Hungarian and Polish Pediatric Immunology working groups were awarded by the Polish Society of Clinical and Experimental Immunology by offering the Ludwik Hirszfeld Medal. The scientific program and the sponsoring difficulties of the 3rd J Project Congress were discussed. It was proposed that alternative venues should be considered. The upcoming workshop on how the ERN-RITA network should be extended to Eastern Europe was announced and the disappointment on the lack of Eastern European member centers were expressed.

At the SC meeting the most important discussion point was the reorganization of the structure of the J Project. With one exception the SC members proposed that a JP Society may be founded. However, it was also suggested that the coming SC meeting should be devoted to an in depth discussion of the new organization. The J Project never expressed any sign of separation from the global PID community, especially not from ESID. However, in this heterogenous subcontinent of Europe the challenges of PID patient care differs greatly from that in the western world, from country to country and even inside countries. This is reality and we saw that clearly when we decided 13 years ago to meet the unique challenges.

László Maródi
The Hungarian Society for Primary Immunodeficiencies (HSPID) was established in 2012 in order to assure a higher level of professional organization and an authentic representation of patients with PID in the country. This legally registered society led by an elected board has had yearly meetings since its establishment. HSPID meetings were occasionally organized as part of the annual meetings of the Hungarian Society of Clinical Microbiology and Infectious Diseases and focused on infection and immunity as strongly related disciplines in medicine and relevant to PIDs. In 2017 the HSPID had a meeting in Budapest at the Clubhouse of the Foundation for Hungarian Rheumatology. Major topics were 1) update of PID registry in Hungary and, in particular, the reporting of patients to the ESID registry, 2) genetic diagnostics of PID, and 3) the extension of the J Project to the Trans-Danubian (western) area of the country, where the number of diagnosed patients is lower than in the eastern part and Budapest. Ad 1: we decided that each PID center should take responsibility to report patients to the ESID registry in contrast to previous practice when all patients were reported by the Debrecen Center. This would assure that patients will be reported by doctors who are permanently taking care of them. Ad 2: It was encouraged that alternative genetic centers should be established in the country and new generation sequencing should be started to cope with the development of the field. It was also disclosed that the genetic diagnostic service provided by the Debrecen Center since 2004, will temporarily be reestablished in a USA-based institution. Ad 3: In Hungary, the realization that recognition and treatment of patients with PIDs show remarkable dif-
ferences in the western and eastern parts of the country, a new project to implement an educational activity should be started. The aim is to target each community hospitals and organize PID focused meetings with patients, nurses, lab workers, and hospital leaders. Ilona Kovacs, Pediatrician in Chief at Ajka Community Hospital was invited to coordinate this project. Lack of appropriate professional interest and knowledge, and neglect of PID patient care is still an existing problem. At the HSPID meeting it was emphasized that joined forces are needed from the part of various PID-focused organizations like the Pediatric Immunology Working Group of the Hungarian Society of Pediatricians and the Hungarian Society for Immunology, the IPOPI member patient group Hungarian Association of Patients with Immunodeficiencies, and other local patient groups, as well as the Hungarian Foundation for Children with Immunodeficiencies. Finally, reports on the scheduled 3rd J Project Congress and the 17th ESID Congress were presented.

László Maródi
Árpád Lányi

Schematic representation of the aim of the J Project West-Hungary educational program. Meetings are scheduled at each County Hospital in the Transdanubian area: Tatabanya, Győr, Szombathely, Zalaegerszeg, Vészprem, Székesfehérvár, Kaposvar, Pecs, Szekszard. In addition, PID awareness events should be organized in different institutions in Budapest.
PROGRAM

October 6

Press conference with participation of:
Birtanov YA, Maródi L, Prodeus AP, Belevtsev MV, Kovzel YF, Morenko MA

Welcome addresses
Birtanov YA, Minister of Health of Kazakhstan Shaydarov MZ, Head of the JSC Medical University of Astana Vento S, Medical director, CF Medical University Center Bekmambetov TN
Maródi L, Founder and leader of the J-Project Ispayeva ZhB, President, Kazakh Association of Allerg/Clin Immunol

Plenary session
The J-project: Successes and prospects for international collaboration Maródi L. (Budapest)
Diagnosis and neonatal screening of primary immunodeficiency Prodeus AP (Moscow)
Modern aspects of immunologic and genetic diagnostics of PID Belevtsev MV, (Minsk)
Replacement therapy in patients with impaired humoral immunity Kovzel YF, Astana City
Immunomodulatory therapy in clinical practice Kostinov MP (Moscow)
The use of sc. immunoglobulin for replacement therapy in PID patients Uglova TA (Minsk)

Plenary session
New approaches to understanding variable immunodeficiency Belevtsev MV, (Minsk)
Vaccination of immunocompromised patients Kostinov MP (Moscow)
Current issues of rehabilitation of RRI children Morenko MA (Astana City)

Parallel sessions
Central Asia Daughters Project session, Laboratory diagnostics of immunodeficiency,
Session of young researches and practic-
ing physicians

**Plenary session**
TREC\KREC for screening immunodeficiency conditions
*Philipenko ML* (Novosibirsk)
Primary immunodeficiency: modern aspects of diagnostics and treatment
*Schneider KV* (Astana City)
Flow cytofluorometry in the diagnosis of primary immunodeficiencies
*Kustova E* (Almaty)
Variable immunodeficiency: data from epidemiological research
*Usenova OP* (Astana City)
Lab diagnostics of primary immunodeficiency conditions
*Belevtsev MV* (Minsk)
Clinical case of SCID with haplo HSCT
*Abileva AB* (Astana City)
Lymphomas in children. Epidemiology and screening for PID
*Kushkova GN* (Astana City)
Allergen-specific immunotherapy to treat pollinosis
*Saltabayeva US* (Astana City)

**Plenary session**
Differential diagnostics in immunodeficiency conditions
*Prodeus AP* (Moscow)
Genetic diagnostics of primary immunodeficiency
*Philipenko ML* (Novosibirsk)
Immunodeficiency: as simple as possible about complex disorders
*Rozenson RI* (Astana City)

**October 7**
School “Interpretation of immune status”
*Nikitin YV* (St Petersburg)
School “Diagnostics of drug hyper-sensitivity”
*Kovzel YF* (Astana City)

**Plenary session**
Transplantation of hematopoietic stem cells in primary immunodeficiencies:
New technologies, trends and prospects
*Balashov DN* (Moscow)
Achievements by HSCT treatment in children in Kazakhstan
*Nurgaliyev DD* (Astana City)
Hematologic masks of patients with primary immunodeficiency
*Manzhurova LN* (Almaty)
Immunograms: Evaluation of cellular immunity
*Nikitin YV* (St. Petersburg)

**Plenary session**
Challenges in diagnosis and treatment of herpesvirus infections
*Skuchalina LN* (Astana City)
Arthritis syndrome in pediatrics
*Abdrakhmanova ST* (Astana City)
Possibilities of personalized anticytokine therapy of rheumatoid arthritis
*Bitanova EJ* (Astana City)
Role of nutrition in forming immunity in children of the first year of life
*Akhmetova SV* (Karaganda)
Summary of Poster presentations
Closing ceremony, certificates
City tour by bus (meeting at the Hotel hall)

*The Hall of the Institute of Mother and Child*
Visiting the Bone Marrow transplantation Unit.
L–R: Tyurina Svetlana (Kazakhstan); Dzhienbekova Cholpon (Kirghizia); Dodova Salikha (Tajikistan); Motusheva Raushan (Kirghizia); Khojaeva Nikzan (Tajikistan); Dair Nurgaliev; László Maródi (Hungary); Davlatova Madina (Tajikistan)

Astana City
The International Scientific and Practical Conference “Actual Issues of Clinical Immunology”, the First Congress of Immunologists of the Republic of Kazakhstan, and the J Project program was held on October 6–7 2017 in Astana, the capital of the Republic of Kazakhstan.

This event was organized by the Kazakh Society of Immunodeficiencies, and the Association of Physicians of Immunologists of the Republic of Kazakhstan. This event was supported by the Ministry of Health of the Republic of Kazakhstan, University Medical Center, Medical University of Astana, and the international J Project.

The scientific-practical conference is devoted to the problems of primary immunodeficiencies, topical issues of clinical immunology in pediatrics and general therapy. Also, within the framework of the conference, a congress of the organization of patients and their parents with primary immunodeficiencies was held. The conference was attended 250 physicians of immunology and allergology, pediatricians, and surgeons.

Leading specialists of the world were invited to the conference to cover modern diagnostic methods, treatment and prevention of immunodeficient conditions.

The conference and congress was supported by the Minister of Health Elzhan Amartanevich Birtanov, who delivered a welcoming speech. Sandro Vento, the medical director of the University Medical Center, László Maródi, the head of the international J Project, Mazhit Zeynullovich Shaidarov the rector of the Medical Academy of Astana, Andrej Prodeus, the well-known professor, and Prof. Zh. the president of the Kazakh Association of Allergologists and Clinical Immunologists directed the famous film director Timur Bekmambetov.

Physicians immunologists from Tajikistan, Uzbekistan, Kyrgyzstan, Turkmenistan came to the meeting. The chairman of the meeting was the famous professor, the head of this project László Maródi. The last international protocols were presented, schools for practical doctors, a section of young scientists were held. The chairman of the Kazakh Society of Immunodeficiencies, the head of the Department of Clinical Immunology, Allergology and Pulmonology of the Republican Diagnostic Center Elena

*L–R: Kadir Omarov (Kazakhstan); Michail Belevtsev (Belarus); László Maródi (Hungary); Andrey Prodeus (Russia); Elena Kovzel (Kazakhstan).*
Kovzel and the head of the Department of Pediatrics No. 1 of the Astana Medical Academy, the main allergist immunologist Astana Marina Morenko made presentations. Within the framework of the conference and the mentor program of the University Medical Center, dozens of consultations of complex and severe patients were conducted by leading professors in the clinics of the University Medical Center.

**Elena Kovzel**
PROGRAM

Primary immunodeficiencies and pulmonary involvement in adults

A Sediva (Prague)
Introduction, Primary Immunodeficiency Working Group by Czech Society for Allergy and Immunology

J Litzman (Brno)
Primary immunodeficiencies in adults

P Kralickova (Hradec Kralove)
Pulmonary manifestation of primary immunodeficiencies in adults, diagnostics and treatment

T Milota (Prague)
Immunodeficiencies in patients with pulmonary involvement

Primary Immunodeficiency Working Group meeting

A Sediva
Introduction, PID group activities in 2017 and discussion

Short presentations from ESID 2017

A Klocperk – deficit kaspázy 8

M Bloomfield – STAT1GOF

R Zachova – STAT3GOF

T Milota – CVID Tly

Z Chovancova – CVID neutrophils

T Freiberger – HEA

E Hlavackova – rare immunodeficiencies

M Svaton – NGS

The Meeting Venue:
Clarion Congress Hotel, Olomouc
SUMMARY

The meeting was organised as a satellite symposium of the XXVI. Congress of Moravian Pneumologists in Olomouc, Czech Republic. The participants were not only pneumologists, but also physicians directly involved in the diagnosis and treatment of patients with PID in the Central-Moravian region. The speakers presented the topics where lung physicians can meet and diagnose patients with primary immunodeficiencies. The presentations were very well accepted and definitively stimulated broader interdisciplinary collaboration between immunologists and pneumologists. The second part of the meeting included presentations of young doctors and scientist, which were previously presented at various international congresses.

Anna Sediva, Jiri Litzman
PROGRAM

SUMMARY

We had organized a J Project Meeting in Van to increase the awareness of primary immunodeficiency (PID) diseases among the pediatricians, family physicians and medical students. The main topic of Van Meeting was “Diagnosis and Treatment of Primary Immunodeficiency”, and Prof László Maródi was with us.

Van J Project Meeting was held on Oct 13, 2017 in Turkey. The meeting was organized with Van University and was primarily focused on the awareness, clinical signs and treatment of PID among the physicians (especially pediatricians) and medical students, also to discuss the importance of early diagnosis in patients with PID, and 120 participants attended the meeting. Prof. László
Maródi gave his lecture about the achievements and future perspectives of the J Project. In discussion, all of the participants discussed the importance of early diagnosis and early treatment of the pediatric and adult patients with PID. I would like to thank all participants and speakers for their contribution for Van J Project Meeting.

Prof. Ismail Reisli
Boat trip to Akhtamar Island
I Reisli, R Reisli, and L Maródi

Speakers’ dinner at Erkoç Restaurant

View from Van Castle

Views from Akhtamar Island

At the House of Van Cat

Traditional Çağ Kebab served by Ismail Reisli, the host of the Meeting

Boat trip to Akhtamar Island
I Reisli, R Reisli, and L Maródi

Van Castle. L–R: Z Çalışkaner, I L Maródi, and D Odabaş
CHISINAU, REP. OF MOLDOVA

November 3, 2017

Host: Svetlana Sciuca
Venue: State University of Medicine and Pharmacy “Nicolae Testemitanu”, Chisinau
Main Topic: The immunity of the child and primary immunodeficiency

PROGRAM

Introduction
Ministry of Health, Labour and Social protection of Republic of Moldova
Boris Gilca
State University of Medicine and Pharmacy “Nicolae Testemitanu”
Ghenadie Curocichin
Science Academy of Republic of Moldova
Eva Gudumac
Semmelweis University, Budapest, Hungary
László Maródi
Department of Pediatrics, University of Chishinau
Svetlana Sciuca

Session 1
Child’s immunity and assessment of immunologic status
The development of the J Project in Central and Eastern Europe
László Maródi (Budapest)
Child’s immunologic system aspects
Svetlana Sciuca (Chisinau)
Genomic aspect of neonatal immunity
Ian Toma (Washington)
Diagnostic methods in immunology
Olimpia Gherman (Chisinau)
Pathomorphologic diagnosis in child’s primary immunodeficiency
Lilia Sinițina (Chisinau)
Novel genetic etiologies of chronic mucocutaneous candidiasis
László Maródi (Budapest)

Session 2
Primary immunodeficiencies
Aspects of vaccinations in children with immunologic disorders
Mihail Kostinov (Moscow)
Immunity of frequently sick child and personalized recovery programmes
Svetlana Sciuca (Chisinau)

Concentrated Biologic Seaweed – the peak of the cellular nutrition.
Michail Kiriac (Québec)

Immunologic insufficiency and immunomodulatory drugs in pediatric practice
EA Degteareva (Moscow)

Luis Bar syndrome
Gheorghe Railean, Rodica Selevestru (Chisinau)

Wiskott-Aldrich syndrome
Aliona Cotoman, Svetlana Sciuca (Chisinau)

Diagnostic steps in hypogammaglobulinemia
Mihaela Bataneant (Timisoara)

Bruton agamaglobulinemia
Rodica Selevestru (Chisinau)

Selective IgA immunodeficiency in children
Cristina Tomacinschii, Svetlana Sciuca (Chisinau)

Mycoplasma infection and immunologic reactivity in children –
Liuba Neamtu (Chisinau)

Diarrhea disease in infant – the manifestations of frequent severe combined immunodeficiencies –
Mihaela Bataneant (Timisoara)

Humoral immune response involvement in bronchic hyperreactivity in children with GERD
Ianoş Adam (Chisinau)

Opening ceremony
SUMMARY

The international PID Meeting “The immunity of the child and primary immunodeficiency” was organized to promote PID care and diagnosis in Moldova. PIDs in children continue to result in remarkable disability in this vulnerable patient population. According to various diagnostic criteria, there are more than 300 PIDs and most of them are genetically confirmed. Obviously, the number of cases of PID identified in a country largely depends on existing diagnostic possibilities. In Moldova, the statistical data on the prevalence of PIDs suggest underdiagnosis.

The international PID practical conference is realized within the project competition of the Academy of Sciences of Moldova under the aegis of the Ministry of Health.

PIDs are mostly rare diseases requiring complex and often sophisticated diagnostic programs, multidisciplinary specialist engagement, international collaboration with specialists with immunology expertise, and immune system disorders. The event brought together professors with an international name from Hungary, USA, Canada, Russia, Romania, academics, researchers, practitioners from the Republic of Moldova (320 participants).

The purpose of the conference was to discuss issues of epidemiology of immunodeficiencies, causative factors, clinical manifestations, exploratory diagnostic criteria, exchange of experience among colleagues from different countries, discussions on the different approaches to the treatment of patients with PIDs. The invited speaker was László Maródi (Hungary) who gave an interesting overview regarding PID achievements and current concepts. The scientific information and practical measurements in this field will be used by pediatricians, family doctors, hematologists, residents and
the reports presented at the scientific conference will serve as a theoretical support for physicians in the clinical, diagnostic and therapeutic conduct of the patient with immunodeficiencies.

The participation of specialists from different countries will allow the establishment of collaborative research relations with the institutions from these countries, the elaboration of the collaboration projects, the continuation of the collaboration in J Proiect. The scientific and social programs of this meeting were highly successful and we would like to thank all participants, especially our distinguished invited speakers. The conference materials were published in “Arta medica” Journal N 4 as scientific support for physicians working in pediatrics, pneumology, clinical immunology.

On November 2, László Maródi visited the Mother and Child Institute, Department of Pediatrics, met with Medical Director Valentin Țurea, Svetlana Sciuca, physicians of the Pneumology Clinic, resident doctors. In this meeting were examined patients with immunodeficiencies and have discussed prospects of cooperation with other centers, to facilitate early diagnosis and treatment.

*Svetlana Sciuca*
PROGRAM

Wiskott-Aldrich syndrome.

I Kondratenko (Moscow)

Severe combined immunodeficiencies.

S Vakhlayrskaya (Moscow)

Hyper IgE syndrome.

O Pachshenko (Moscow)

SUMMARY

Allergology-Immunology is a combined specialty in Russia, so overwhelming majority of physicians are mainly allergologists. This is the main reason for educational programs focusing on the problems of diagnostics, pathophysiology and treatment of primary immunodeficiencies.

We had about 90 participants from all Russian regions: Moscow and Moscow region, Ekaterinburg, Chelyabinsk, Ulan-Ude (Buryatia), Kazan (Tatarstan), and many other towns. All participants enjoyed the meeting. After the lectures we had very good dialog and discussion with our colleagues. Diagnostic and legal questions were discussed. We proposed the new concept of warning signs which include non infectious features. Several specialists from different regions of Russia remembered that they have had patients with signs of immunodeficiency.

These specialists should send us the case reports of patients with presumed PID. Up to 5-6 new patients are admitted in our Department every time after similar conferences. As a rule, PID is confirmed in 2-3. Looking forward our future collaboration. Irina Kondratenko
PRISTINA, KOSOVO

December 16, 2017

Host: Vlora Ismaili-Jaha
Venue: Emerald Hotel, Pristina
Main Topic: Primary Immunodeficiencies Diagnostic and Therapeutic Challenges

PROGRAM

Session 1
Agamaglobulinemia: diagnostic and therapeutic challenges
S Spahiu-Konjusha
Pulmonary manifestations of PID
E Kostaqi
Alternative treatment with Ig to PID and SCID
B Abrashi
Two sisters with ataxia-teleangiectasia
S Hasani
Immunodeficiency phenotypes
V Grajcevci-Uka
Questions and Discussions

Session 2
PID in Albania
G Kuli-Lito
Severe immunodeficiencies
L Spahiu
Neutropenia and immunodeficiencies
R Maqastena-Maxhuni
PID diagnostics
L Neziri-Ahmeti
Bruton’s disease
D Qosaj

Questions and Discussions
Closing

SUMMARY

The first J Project Meeting in Kosovo was organized together with colleagues and participants from Albania, in particular with the help of Prof. Georghina Kuli-Lito. We had 105 participants from all over Kosovo, mostly pediatricians and immunologists. The meeting received accreditation from the Ministry of Health with the CME credits. The socioeconemic condition in Kosovo is far from optimal to develop a reasonable level of PID diagnostics and treatment in the near future. However, with the help and professional collaboration with colleagues under the J Project program we should be able to make a significant difference and we are determined to join the European PID community in this particular field of medicine. We hope this meeting was an important first step towards and established PID care in Kosovo.

Vlora Ismaili-Jaha
The Clock Tower in Pristina

View of Pristina

The Meeting Room in Hotel Emerald
<table>
<thead>
<tr>
<th>City (Country)</th>
<th>Organizer</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2004</strong></td>
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<tr>
<td>1. Targu Mures, Romania</td>
<td>Csilla Todea</td>
<td>March 11–12</td>
</tr>
<tr>
<td>2. Prague, Czech Republic</td>
<td>Anna Sediva</td>
<td>May 10–11</td>
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<tr>
<td>3. Belgrade, Serbia/Montenegro</td>
<td>Srdjan Pasic</td>
<td>June 11–12</td>
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<tr>
<td>4. Skopje, Macedonia</td>
<td>Katarina Stavrik</td>
<td>September 17–18</td>
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<tr>
<td>5. Kyiv, Ukraine</td>
<td>Alla Volokha</td>
<td>November 18–19</td>
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<tr>
<td>6. Zakopane, Poland</td>
<td>Ewa Bernatowska</td>
<td>December 16–17</td>
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<tr>
<td><strong>2005</strong></td>
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<td>7. Sofia, Bulgaria</td>
<td>Elissaveta Naumova</td>
<td>April 15–16</td>
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<tr>
<td>8. Prague, Czech Republic</td>
<td>Anna Sediva</td>
<td>May 9–10</td>
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<tr>
<td>9. Gdansk, Poland</td>
<td>Ewa Bernatowska</td>
<td>September 23–24</td>
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<tr>
<td>10. Debrecen, Hungary</td>
<td>László Maródi</td>
<td>November 4–5</td>
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<tr>
<td>11. Lviv, Ukraine</td>
<td>Larysa Kostyuchenko</td>
<td>November 25</td>
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<tr>
<td>12. Oradea, Romania</td>
<td>Zoltan Ellenes</td>
<td>December 20</td>
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<tr>
<td>14. Prague, Czech Republic</td>
<td>Anna Sediva</td>
<td>May 8–9</td>
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<tr>
<td>15. Bucharest, Romania</td>
<td>Nicolae Iagaru</td>
<td>June 9–10</td>
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<td>16. Minsk, Belarus</td>
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<td>November 9–10</td>
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<td>Apr 19–20</td>
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<td>Aurica Rugina</td>
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<td>22. Ljubljana, Slovenia</td>
<td>Tadej Avcin</td>
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<td>23. Odessa, Ukraine</td>
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<td>24. Sunny Beach, Bulgaria</td>
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<td>25. Sarajevo, Bosnia-Herzegovina</td>
<td>Velma Mulaosmanovic</td>
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<td>27. Riga, Latvia</td>
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<td>Fazil Orhan &amp; Ismail Reisli</td>
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2012

61. Lillafüred, Hungary Miklós Szolnoky January 20–21
3rd J Project Steering Committee Meeting
63. Rostov-on-Don, Russia Ludmila Sizyakina March 16
64. Moscow, Russia Irina Kondratenko March 29
65. Chernigov, Ukraine Liudmyla Chernyshova April 5–6
66. Tallinn, Estonia Krista Ress April 19
67. Tehran, Iran Asghar Aghamohammadi April 22
68. Bratislava, Slovakia Peter Ciznar April 27
69. Diyarbakir, Turkey Ismail Reisli May 12
70. Prague, Czech Republic Anna Sediva May 14–15
71. Konya, Turkey Ismail Reisli May 26–27
72. Warsaw, Poland Ewa Bernatowska June 1–2
73. Sibiu, Romania Sorin Iurian June 1–2
74. Tzigov Chark Elissaveta Naumova June 8–9
75. Astana City, Kazakhstan Panteley Popandopulo June 12–15
76. Tyumen, Russia-Siberia Irina Tuzankina July 1–2
77. Ljubljana, Slovenia Tadej Avcin September 14–15
78. Tehran, Iran Nima Rezaei October 13–14
79. Timisoara, Romania Mihaela Bataneant October 25–26
80. Minsk, Belarus Mikhail Belevtsev November 17
81. Ufa, Russia Irina Tuzankina November 23
82. Sanliurfa, Turkey Ismail Reisli November 25
83. Krakow, Poland Ewa Bernatowska December 15

2013

84. Mukachevo, Ukraine Liudmyla Chernyshova April 18
85. Tehran, Iran Nima Rezaei April 23
86. Bratislava, Slovakia Peter Ciznar April 24
87. Debrecen, Hungary László Maródi April 26
88. Ljubljana, Slovenia Tadej Avcin May 9
89. Prague, Czech Republic Anna Sediva May 13–14
90. Moravia, Czech Republic Jiri Litzman May 31
91. Budapest, Hungary László Maródi May 31–June 1
4th J Project Steering Committee Meeting
92. Cracow, Poland Ewa Bernatowska September 20–21
93. Szolnok, Hungary Zsuzsa Horváth October 5
94. Tehran, Iran Nima Rezaei October 12–13
95. Ptuj, Slovenia Tadej Avcin October 18–19
96. Krasnoyarsk, Siberia, Russia Irina Tuzankina October 22
97. Malatya, Turkey Ismail Reisli November 16
98. Budapest, Hungary László Maródi November 22
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<td>Antalya, Turkey</td>
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<td>Ismail Reisli</td>
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<td>102. Zagazig, Egypt</td>
<td>Mohamed Almaky</td>
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<td>103. Tehran, Iran</td>
<td>Nima Rezaei</td>
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<td>&amp; Asghar Aghamohammadi</td>
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<td>104. Poltava, Ukraine</td>
<td>Liudmyla Chernyshova</td>
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<td>Tatiana Nasyrina</td>
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<td>108. Varna, Bulgaria</td>
<td>Elissaveta Naumova</td>
<td>October 6</td>
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<td>109. Catez, Slovenia</td>
<td>Tadej Avčin</td>
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<td>October 24–25</td>
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<td>Ewa Bernatowska</td>
<td>October 24–25</td>
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<td>113. Pardubice, Czech Republic</td>
<td>Anna Sediva</td>
<td>November 11</td>
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<td>114. Nizhny Novgorod, Russia</td>
<td>Tatiana Nasyrina</td>
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<td>115. Sibiu, Romania</td>
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<td>Dilara Kocacık Uygun &amp; Demet Hafızoğlu</td>
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<td>120. Bratislava, Slovakia</td>
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<td>129. St. Petersburg, Russia</td>
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<td>130. Perm, Russia</td>
<td>Irina Tuzankina</td>
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<td>131. Timisoara, Romania</td>
<td>Margit Serban</td>
<td>September 3–4</td>
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<td>132. Tehran, Iran</td>
<td>Nima Rezaei</td>
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<td>133. Tirana, Albania</td>
<td>Georgina Kuli-Lito</td>
<td>November 20–21</td>
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134. Bořetice, Czech Republic  |  Anna Sediva  |  November 19–20
135. Plovdiv, Bulgaria  |  Marianna Murdjeva  |  November 20

2016

136. Warsaw, Poland  |  Ewa Bernatowska  |  February 18
137. Moscow, Russia  |  Irina Kondratenko  |  February 25
138. Antalya, Turkey  

2nd J Project Congress  
7th J Project Steering Committee Meeting
139. Tehran, Iran  |  Nima Rezaei  |  April 23–24
& Ashgar Agamohammadi
140. Bratislava, Slovakia  |  Peter Ciznar  |  April 27
141. Kaunas, Lithuania  |  Brigitas Sitkauskiene  |  May 4–5
142. Ljubljana, Slovenia  |  Tadej Avcin  |  May 14
143. Konya, Turkey  |  Ismail Reisli  |  May 26
144. Chernivtsi, Ukraine  |  Liudmyla Chernishova  |  May 26–27
145. Kaliningrad, Russia  |  Irina Tuzankina  |  June 27–30
146. Pilsen, Czech Republic  |  Anna Sediva  |  October 12
& Jiri Litzman
147. Konya, Turkey  |  Ismail Reisli  |  October 26
148. Sofia, Bulgaria  |  Elissaveta Naumova  |  October 28
149. Chisinau, Moldova  |  Svetlana Sciuca  |  November 25

2017

150. Budapest, Hungary  
7th J Project Steering Committee Meeting
151. Konya, Turkey  |  Ismail Reisli  |  April 18
152. Kropivnitskyi, Ukraine  |  Liudmyla Chernyshova  |  April 20–21
153. Tehran, Iran  |  Nima Rezaei  |  April 22–29
154. Kaunas, Lithuania  |  Brigitas Sitkauskiene  |  April 26
155. Bratislava, Slovakia  |  Peter Ciznar  |  May 3
156. Eskisehir, Turkey  |  Ismail Reisli  |  May 5
157. Ljubljana, Slovenia  |  Tadej Avcin  |  May 13
158. Baku, Azerbaijan  |  Gulnara Nasrullayeva  |  June 1
159. Warsaw, Poland  |  Ewa Bernatowska  |  June 7
160. Tsigov Chark, Bulgaria  |  Marianna Murdjeva  |  June 16–18
161. Chelyabinsk, Russia  |  Irina Tuzankina  |  August 27
162. Sofia, Bulgaria  |  Elissaveta Naumova  |  September 9
163. Edinburgh, UK  
9th J Project Steering Committee Meeting
164. Budapest, Hungary  |  László Maródi  |  September 22
165. Astana City, Kazakhstan  |  Elena Kovzel  |  October 6–7
166. Olomouc, Czech Republic  |  Anna Sediva  |  October 10
<table>
<thead>
<tr>
<th>Meeting venue</th>
<th>Organizer(s)</th>
<th>Schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>167. Van, Turkey</td>
<td>Ismail Reisli</td>
<td>October 13–14</td>
</tr>
<tr>
<td>168. Chisinau, Rep. of Moldova</td>
<td>Svetlana Sciuca</td>
<td>November 3</td>
</tr>
<tr>
<td>169. Moscow, Russia</td>
<td>Irina Kondratenko</td>
<td>November 24</td>
</tr>
<tr>
<td>170. Pristina, Kosovo</td>
<td>Vlora Ismaili-Jaha</td>
<td>December 16</td>
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</table>

Number of JP Meetings between 2004–2017: 170

J Project Meetings 2018

<table>
<thead>
<tr>
<th>Meeting venue</th>
<th>Organizer(s)</th>
<th>Schedule</th>
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<tbody>
<tr>
<td>172. Konya, Turkey</td>
<td>Ismail Reisli</td>
<td>March 20</td>
</tr>
<tr>
<td>173. Bratislava, Slovakia</td>
<td>Peter Ciznar</td>
<td>April 10–11</td>
</tr>
<tr>
<td>174. St. Petersburg, Russia</td>
<td>Marina Guseva</td>
<td>April 4</td>
</tr>
<tr>
<td>175. Minsk, Belarus</td>
<td>Michael Belevtsev</td>
<td>April 19–20</td>
</tr>
<tr>
<td>176. Tehran, Iran</td>
<td>Nima Rezaei</td>
<td>April 21–23</td>
</tr>
<tr>
<td>177. Kiev, Ukraine</td>
<td>Liudmyla Chernishova &amp; Alla Volokha</td>
<td>April 26–27</td>
</tr>
<tr>
<td>178. Almaty, Kazakhstan</td>
<td>Zhanat Ispayeva</td>
<td>April 27</td>
</tr>
<tr>
<td>179. Kaunas, Lithuania</td>
<td>Brigita Sitkauskiene</td>
<td>May 2</td>
</tr>
<tr>
<td>180. Batman, Turkey</td>
<td>Ismail Reisli</td>
<td>May 3</td>
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<tr>
<td>181. Warsaw, Poland</td>
<td>Ewa Bernatowska</td>
<td>May 10–11</td>
</tr>
<tr>
<td>182. Ljubljana, Slovenia</td>
<td>Tadej Avcin</td>
<td>May 12</td>
</tr>
<tr>
<td>183. Skopje, Rep. Macedonia</td>
<td>Kristina Mironska</td>
<td>May 18</td>
</tr>
<tr>
<td>184. Astana City, Kazakhstan</td>
<td>Elena Kovzel</td>
<td>June 9</td>
</tr>
<tr>
<td>185. Tsigov Chark, Bulgaria</td>
<td>Elissaveta Naumova &amp; Mariana Murdjeva</td>
<td>June 15–17</td>
</tr>
<tr>
<td>187. Ekaterinburg, Russia</td>
<td>Irina Tuzankina</td>
<td>Sep 18</td>
</tr>
<tr>
<td>188. Uzbekistan, Tashkent</td>
<td>Diloram Musahodzhayeva, Irina Tuzankina</td>
<td>Sep 24</td>
</tr>
<tr>
<td>189. Uzbekistan, Bukhara</td>
<td>Diloram Musahodzhayeva, Sep 26</td>
<td></td>
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<tr>
<td>190. Pristhina, Kosovo</td>
<td>Vlora Ismaili-Jaha</td>
<td>Sep</td>
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<tr>
<td>191. Urfa, Turkey</td>
<td>Ismail Reisli</td>
<td>Oct 5–6</td>
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<tr>
<td>192. Brno, Czech Republic</td>
<td>Anna Sediva</td>
<td>Oct 10</td>
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<tr>
<td>194. Tirana, Albania</td>
<td>Georgina Kuli-Lito</td>
<td>Dec</td>
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<tr>
<td>195. Sofia, Bulgaria</td>
<td>Elissaveta Naumova &amp; M Nikolova</td>
<td>Oct</td>
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<tr>
<td>196. Tbilisi, Georgia</td>
<td>Karaman Pagava</td>
<td>Oct 27–28</td>
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<tr>
<td>197. Dushanbe, Tajikistan</td>
<td>Kosimov Abduloevich</td>
<td>Nov</td>
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<tr>
<td>198. Sarajevo, Bosnia&amp;H</td>
<td>Velma Mulaosmanovic</td>
<td>Nov</td>
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<tr>
<td>199. Herceghalom, Hungary</td>
<td>Laszlo Marodi, Katalin Vamos</td>
<td>Nov</td>
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### J Project Steering Committee Meetings

<table>
<thead>
<tr>
<th>Year</th>
<th>Date</th>
<th>City</th>
<th>Venue</th>
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</thead>
<tbody>
<tr>
<td>2010</td>
<td>Sep 10–11</td>
<td>Budapest</td>
<td>Hotel Ramada</td>
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<tr>
<td>2011</td>
<td>Mar 10–11</td>
<td>Debrecen</td>
<td>Hotel Thermal Aquaticum</td>
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<tr>
<td>2012</td>
<td>Jan 27–28</td>
<td>Budapest</td>
<td>Hotel Mercure Korona</td>
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<tr>
<td>2013</td>
<td>May 31–Jun 1</td>
<td>Budapest</td>
<td>Grand Hotel Margitsziget</td>
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<tr>
<td>2014</td>
<td>Mar 12–14</td>
<td>Antalya</td>
<td>Hotel Rixos Lares</td>
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*At the 50th J Project Meeting – Celebration*

<table>
<thead>
<tr>
<th>Year</th>
<th>Date</th>
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<th>Venue</th>
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<tbody>
<tr>
<td>2015</td>
<td>Mar 5–6</td>
<td>Budapest</td>
<td>Grand Hotel Margitsziget</td>
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<td>2016</td>
<td>Mar 2</td>
<td>Antalya</td>
<td>Hotel Sherwood</td>
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<tr>
<td>2017</td>
<td>Mar 2–3</td>
<td>Budapest</td>
<td>Hotel Flamenco</td>
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<tr>
<td>2017</td>
<td>Sep 18</td>
<td>Edinburgh</td>
<td>Congress Center</td>
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*At the 100th J Project Meeting – Declaration*

### J Project Executive Committee Meeting

<table>
<thead>
<tr>
<th>Year</th>
<th>Date</th>
<th>City</th>
<th>Venue</th>
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<tbody>
<tr>
<td>2016</td>
<td>Sep 23</td>
<td></td>
<td>Congress Center</td>
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### The J Project Steering Committee

<table>
<thead>
<tr>
<th>Name</th>
<th>E-mail</th>
<th>City</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Georgina KULI-LITO</td>
<td><a href="mailto:gkuli_lito@hotmail.com">gkuli_lito@hotmail.com</a></td>
<td>ALBANIA</td>
<td>Tirana</td>
</tr>
<tr>
<td>Gulnara NASRULLAYEVA</td>
<td><a href="mailto:g.nasrullayeva@hotmail.com">g.nasrullayeva@hotmail.com</a></td>
<td>AZERBAIJAN</td>
<td>Baku</td>
</tr>
<tr>
<td>Michail BELEVTSYEV</td>
<td><a href="mailto:believtsyev_m@mail.ru">believtsyev_m@mail.ru</a></td>
<td>BELARUS</td>
<td>Minsk</td>
</tr>
<tr>
<td>Svetlana SHARAPOVA</td>
<td><a href="mailto:sharapovasv@gmail.com">sharapovasv@gmail.com</a></td>
<td>BELARUS</td>
<td>Minsk</td>
</tr>
<tr>
<td>Velma SELMANOVICH</td>
<td><a href="mailto:velmanulaosmanovic@hotmail.com">velmanulaosmanovic@hotmail.com</a></td>
<td>B&amp;H</td>
<td>Sarajevo</td>
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<tr>
<td>Elissaveta NAUMOVA</td>
<td><a href="mailto:naumovaej@gmail.com">naumovaej@gmail.com</a></td>
<td>BULGARIA</td>
<td>Sofia</td>
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<tr>
<td>Jadranka KELECIC</td>
<td><a href="mailto:jkelecic17@gmail.com">jkelecic17@gmail.com</a></td>
<td>CROATIA</td>
<td>Zagreb</td>
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<tr>
<td>Anna SEDIVA</td>
<td><a href="mailto:AnnaSediva@fnmotol.cz">AnnaSediva@fnmotol.cz</a></td>
<td>CZECH REP.</td>
<td>Prague</td>
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<tr>
<td>Jiri LITZMAN</td>
<td><a href="mailto:jiri.litzman@fnusa.cz">jiri.litzman@fnusa.cz</a></td>
<td>CZECH REP.</td>
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<tr>
<td>No.</td>
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<tr>
<td>10</td>
<td>Aisha EL-MARSAFY</td>
<td>EGYPT</td>
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<td>Nermeen GALAL</td>
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<td>László MARÓDI</td>
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<td>Debrecen</td>
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<td>17</td>
<td>Asghar AGHAMOHAMMADI</td>
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<td>Nima RESAEI</td>
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<td>Hassan ABOLHASSANI</td>
<td>IRAN</td>
<td>Tehran</td>
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<tr>
<td>20</td>
<td>Elena KOVZEL</td>
<td>KAZAHSTAN</td>
<td>Astana City</td>
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<td>21</td>
<td>Vlora ISMAILI-YAHA</td>
<td>KOSOVO</td>
<td>Prishtin</td>
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<tr>
<td>22</td>
<td>Tatjana PROKOFJEVA</td>
<td>LATVIA</td>
<td>Riga</td>
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<td>Brigita SITKAUSKIENE</td>
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<td>Ewa BERNATOWSKA</td>
<td>POLAND</td>
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<td>Malgorzata PAC</td>
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<td>26</td>
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<tr>
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<td>MACEDONIA</td>
<td>Skopje</td>
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<td>28</td>
<td>Svetlana SCIUA</td>
<td>MOLDOVA</td>
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<td>29</td>
<td>Margit SERBAN</td>
<td>ROMANIA</td>
<td>Timisoara</td>
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<td>30</td>
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<td>31</td>
<td>Alexander PISHCHALNIKOV</td>
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<td>Irina KONDRAVENKO</td>
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<td>Moscow</td>
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</tbody>
</table>
33. Marina GUSEVA
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UKRAINE  Lviv

The J Project Executive Committee

L Maródi  Chair of EC and JPC3; Website, registry and sponsoring
I Reisli  Vice Chair of EC and JPC3; Chair of J Daughters Anatolia
A Elmarsafy  Ethical issues; Chair of J Daughters Egypt Project
N Rezaei  JP Juniors mentorship; Chair of J Daughters Persia Project
E Kovzel  Chair of J Daughters Central Asia Project
I Tuzankina  Chair of J Daughters Siberia Project
E Naumova  Genetic diagnostics WG; Bulgaria–Macedonia–Greece–
E Bernatowska  Clinical studies WG; Poland
B Sitkauskiene  Baltic Countries
M Serban  Ethical issues; Romania–Rep. of Moldova
P Ciznar  Clinical studies WG; Czech Republic–Slovakia
T Avcin  Genetic diagnostics WG; Slovenia–Croatia–Bosnia/Herzegovina–
Serbia
K Vámos  General Secretary of the J Project
Links

The J Project (JP)
http://www.jprojectnetwork.com

Jeffrey Modell Foundation (JMF)
http://www.info4pi.org

European Society for Immunodeficiencies (ESID)
http://www.esid.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

African Society for Immunodeficiencies (ASID)
http://www.asid.ma

Latin American Society for Immunodeficiencies (LASID)
http://www.lasid.org

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

Clinical Immunology Society (CIS)
http://www.clinimmsoc.org

American Academy of Allergy & Asthma and Immunology (AAAAI)
http://www.aaaai.org