

THE J PROJECT

EDITOR:

Melinda Erdős

CO-EDITORS:

*Asghar Aghamohammadi, Tadej Avcin, Ewa Bernatowska,
Liudmyla Chernyshova, Peter Ciznar, Vlora Ismaili-Jaha, Irina Kondratenko,
Elena Kovzel, Jiri Litzman, Mariana Murdjeva, Gulnara Nasrullayeva,
Elissaveta Naumova, Yelena Nemirovskaya, Alexander Pishchalnikov, Ismail Reisli,
Nima Rezaei, Anna Sediva, Svetlana Sciuca, Brigita Sitkauskiene, Irina Tuzankina,
Katalin Vámos, and László Maródi*

March 2018

For further details: www.jprojectnetwork.com

Foreword	3
J Project Meetings in 2017	4
Budapest, Hungary	5
Konya, Turkey	9
Tehran, Iran	11
Kaunas, Lithuania	14
Bratislava, Slovakia	17
Eskisehir, Turkey	18
Ljubljana, Slovenia	20
Kropivnitskyi, Ukraine	22
Baku, Azerbaijan	25
Warsaw, Poland	26
Tsigov Chark, Bulgaria	28
Chelyabinsk, Russia	32
Plovdiv, Bulgaria	35
Edinburgh, UK	37
Budapest, Hungary	39
Astana City, Kazakhstan	41
Olomouc, Czech Republic	46
Van, Turkey	48
Chisinau, Rep. of Moldova	51
Moscow, Russia	55
Pristina, Kosovo	56
J Project Meetings 2004–2017	58
J Project Meetings 2018	63
J Project Steering Committee Meetings	64
J Project Executive Committee Meeting	64
The J Project Steering Committee	64
The J Project Executive Committee	66
Links	67

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 J Project 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

City (<i>Country</i>)	Date
1. Budapest, Hungary J Project Steering Committee Meeting	March 1–2
2. Konya, Turkey	April 17
3. Tehran, Iran	April 21–23
4. Kaunas, Lithuania	April 26
5. Bratislava, Slovakia	May 3
6. Eskisehir, Turkey	May 5
7. Ljubljana, Slovenia	May 13
8. Kropivnitskyi, Ukraine	May 18–19
9. Baku, Azerbaijan	June 1
10. Warsaw, Poland	June 7–10
11. Tsigov Chark, Bulgaria	June 16–18
12. Chelyabinsk, Russia	August 27
13. Plovdiv, Bulgaria	September 8–10
14. Edinburgh, UK J Project Steering Committee Meeting	September 12
15. Budapest, Hungary	September 22
16. Astana City, Kazakhstan	October 6–7
17. Olomouc, Czech Republic	October 10
18. Van, Turkey	October 13–14
19. Chisinau, Rep. of Moldova	November 3
20. Moscow, Russia	November 24
21. Pristina, Kosovo	December 16

Hosts: László Maródi, Katalin Vámos
Venue: Hotel Flamenco, Budapest
Main Topic: 8th J Project Steering Committee Meeting

PROGRAM

 8 th J Project Steering Committee Meeting Hotel Flamenco, Budapest, 2017 AGENDA		
Wednesday March 1, 2017		
18:00	The message of the J Project medical cooperation program István Maros, Ministry of State for Security Policy and International Cooperation, Ministry of Foreign Affairs and Trade, Budapest	
18:15	Comments and discussion	
18:30	Challenges of genetic diagnostics of human diseases András Kósa, Semmelweis University Budapest	
18:45	Dinner in Danubius Hotel Flamenco	
Thursday March 2, 2017		
09:00	Welcome	K Vámos
09:05	SC Meetings 2010-2017	L Maródi
09:15	Country update on PID genetics and treatment - in line with the Antalya Declaration	All
10:30	Breakfast	
11:00	Country update on PID genetics and treatment - in line with the Antalya Declaration	All
13:00	Lunch	
14:00	PID research projects WHIM CGD HIES	K Mészáros, G Markai, M Szegedi, M Jaksits, L Maródi
14:10	J Project Booklet 2016	All
14:25	J Project Meetings scheduled for 2017	All
14:30	J Project Junior Meetings 2016-2017	S Shasapova, N Resaii
14:40	J Project Congress 2018	K Vámos
15:00	Breakfast	
15:30	Collaboration with ESID, CIS, and ASID	A Sediva, L Maródi, A Elmansaly
16:00	J Project Journals: JoCI, CEJ	E Bernatowska, L Maródi
16:15	Strategic proposals for the future	All
16:50	Conclusion and closing	L Maródi
19:00	Dinner at Boat Restaurant Spoon	

SUMMARY

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





Miklós Szolnoky



Jadranka Kelecic



László Maródi



Anna Sediva



Aisha El-Marsafy



Elissaveta Naumova



Michail Belevtsev



András Falus and István Mikola



*Gulnara
Nasrullayeva*



L: T Avcin, J Litzman



A Simboteanu




Participants of the 8th SC Meeting:

(L–R): F Peissker, N Rezaei, P Ciznar, M Szolnoky, C Hermann, A Simboteanu, J Litzman, A Elmarsafy, T Avcin, M Markovic, I Kondratenko, A Sediva, T Prokofjeva, M Serban, A Aghamohammadi, C Jendrsczok, M Bataneant, K Mironska, G Nasrullajeva, E Thomas, E Naumova, A Volokha, K Ashur, L Chernishova, M Pac, G Markelj, E Bernatowska, I Tuzankina, M Skomska, A Bondarenko, I Savchak, L Kostyuchenko, M Dolgikh, M Belevtsev, L Maródi, K Abduloevich, K Vámos

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

PROGRAM



Primer İmmün Yetmezlik Tanısı ve Tedavisi
Diagnosis and treatment of Primary Immunodeficiency

<p>Düzenleme Kurulu (Organization)</p> <p>Prof. Dr. Ismail Reisli Necmettin Erbakan University</p> <p>Prof. Dr. Zafer Çalıkaner Necmettin Erbakan University</p> <p>Doç. Dr. Sevgi Keleş Necmettin Erbakan University</p> <p>Communication Prof. Dr. Ismail Reisli Necmettin Erbakan University Meram Medical School Pediatric Immunology and Allergy 42080, KONYA</p> <p>Tel: +90 332 223 76 44 +90 332 223 73 05 +90 332 223 70 86</p> <p>Date: April 17, 2017 Hour: 09.00-12.00 Venue : Meram Tıp Fakültesi Conference Room</p>	<p>Chair Ismail Reisli</p> <p>09.00-09.20 Diagnosis of PID Şükrü Nail Güner</p> <p>09.20-09.40 Evaluation of PID patients in Konya Ismail Reisli</p> <p>09.40-10.00 PID in Adults Zafer Çalıkaner</p> <p>Coffee Break</p> <p>10.30-11.15 Immune dysregulation Talat Chatila</p> <p>11.15-11.45 The Turkish-Boston cohort and Hyper IgE syndrome Sevgi Keleş</p> <p>11.45-12.00 Discussion</p>
--	---

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.

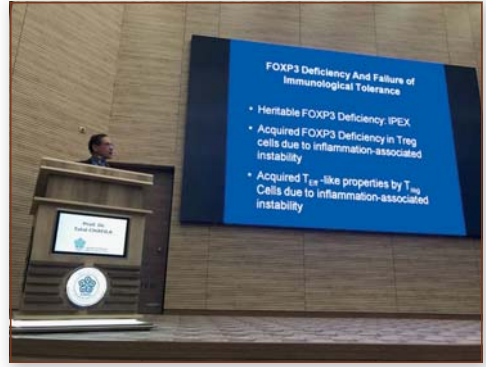
Konya J Project Meeting was organized with Necmettin Erbakan University and Harward University, and was primarily focused on the awareness, clinical signs and treatment of PIDs among the physicians (especially pediatricians) and medical students. The importance of early diagnosis in patients with PIDs 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



Zafer Caliskaner



Talal Chatila



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

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 Bermanian

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 Parvaneh

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 Mahdavi

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

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

Signs and treatment standards of congenital angioedema

J Staikuniene

Supporting self-care for patients and their families

M Jusinskaite

Interactive discussion



Soup bubbles and alchemic performances





Brigita Sitkauskienė presenting clinical cases

SUMMARY

This J Project Meeting was organized by the Center of Primary Immuno-deficiency, 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 Sitkauskienė*, 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 Sitkauskienė* 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



Host: Peter Ciznar**Venue:** Austria Trend Hotel, Bratislava**Main Topic:** 7th Symposium on Primary Immunodeficiencies

PROGRAM

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



Peter Ciznar

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

PROGRAM

ESID PROJECT

Primer İmmün Yetmezlik Tanısında İpuçları
Diagnostic clues for Primary Immunodeficiency

Düzenleme Kurulu (Organization)
 Prof. Dr. Ismail Reisli
 Necmettin Erbakan University
 Konya

Prof. Dr. Abdülkadir Koçak
 Osman Gazi University
 Eskişehir

Chair : Abdülkadir Koçak

13.00-13.30 Diagnostic clues for PID
 Ismail Reisli

13.30-13.45 Treatment of PID
 Esra Hazer Sayar

13.45-14.00 Discussion

Communication
 Prof. Dr. Ismail Reisli
 Necmettin Erbakan University
 Mehmet Akif Ersoy
 Pediatric Immunology and Allergy
 42080, KONYA
 Tel: +90 332 223 76 44
 +90 332 223 73 05

Date: May 05, 2017
Hours: 13.00-14.00
Venue: Osman Gazi Medical School
 Conference Room / Eskişehir

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

Host: Tadej Avcin
Venue: University Children's Hospital, Ljubljana
Main Topics: Physical activity of patients with PID, Travelling with SCIG, Reports from ENCA, IPOPI and National society of patients with PID

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



Happy get together



Host: Liudmyla Chernyshova
Venue: Conference Hall of Hotel Reikartz, Kropyvnytskyi
Main Topic: Primary immune deficiencies in practice of pediatricians and family doctors: The XIII Ukrainian J Project Meeting

PROGRAM

May 18

Opening, Greetings

Pediatric immune deficiencies in Ukraine, according to the status of January 1, 2017

LI Chernyshova (Kyiv)

Pneumonia as a manifestation of immune deficiency

YS Stepanovskyy (Kyiv)

Atopic dermatitis – indications for referral to a pediatric immunologist

LI Chernyshova (Kyiv)

Microcephaly as a manifestation of immune deficiency

LV Kostyuchenko (Lviv)

Sinopulmonary infections – when to refer to a pediatric immunologist

FI Lapii (Kyiv)

Fungal infections in children – when immune deficiency can be considered

AV Bondarenko (Kyiv)

Primary immune deficiencies in Kirovohrad region

NV Shyshkanova (Kropyvnytskyi)

HHV6 in children: doctor's tactics

AP Volokha (Kyiv)

Preparations of immunoglobulins produced in Ukraine

AR Rybakova (Kyiv)

Methods for genetic diagnosis of primary immune deficiencies.

GD Teleheiev, M Dybkov (Kyiv)

Previous consensus treatment protocol of PFAPA syndrome

YS Stepanovskyy (Kyiv)

Mini-movie

Methods of subcutaneous immunoglobulin use

May 19

Transplantation of bone marrow stem cells in Belarus

MV Belevtsev (Minsk)

Neutropenic patients' treatment – multidisciplinary approach

NV Kavardakova (Kyiv)

Transplantation of bone marrow stem cells in Ukraine

SB Donskaya, OV Ryzhak (Kyiv)

Information on work of «Rare immune diseases» patients organization

H Pavuk (Chernivtsi)

Project RAPID

SA Beglaryan (Kyiv)

Discussion

Members' meeting of the Ukrainian Association of Pediatric Immunology

Closing of the event

SUMMARY

On May 18–19, 2017, the 13th Ukrainian scientific and practical symposium entitled “Primary immune deficiencies in practice of pediatricians and family doctors” took place in the city of Kropyvnytskyi (former Kirovohrad) with foreign participation



*Organizers of the J Project Meeting – members of Ukrainian Association of Pediatric Immunology (UAPI)
L–R: S. Beglaryan, F. Lapiy, A. Volokha, L. Chernyshova, V. Chernyshov, Y. Stepanovskiy*



Liudmyla Chernyshova presents master class on PID diagnostics to physicians from Kropyvnytskyi region

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 Chernyshova*, 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 Stepanovskiy* (Kyiv), *FI Lapii* (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



*Pediatric immunologists from all regions of Ukraine.
Behind, Kropyvnytskyi city theater building where first professional
Ukrainian theater was opened*

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 pa-
tient 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*

Host: Ewa Bernatowska
Venue: Airport Okęcie Hotel, Warsaw
Main Topic: Advances in Diagnosis and Therapy of PID

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 Brodzski (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)



Jacek Roliński, President of the Polish Society for Experimental Immunology



László Maródi, Jacek Roliński, Ewa Bernatowska

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 established 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



The Ludwik Hirszfeld medal



László Maródi with Polish immunologists

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 Sarafian



Mariana Murdjeva

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-



Elissaveta Naumova



View from Tsigov Chark: Lake Batak

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

Hosts: Irina Tuzankina
Venue: Congress Hotel “Malachite”, Chelyabinsk
Main Topic: PID Pathology and novel treatment options

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

**27-30 August 2017
Chelyabinsk**

**XIV conference
of Ural Immunologists**

Dear colleagues!

Russian Society of Immunology (RSI) invites you from August 27 to August 30, 2017 in Chelyabinsk to participate in the XIV Conference of Immunologists of the Urals with international participation, which will be held at the South Ural State Medical University.

THE CONFERENCE PROGRAMME INCLUDES:

- The scientific part devoted to the problems of fundamental and clinical immunology with the involvement of specialists in the field of immunopharmacology, immunology of reproduction, immunobiotechnology, immunodiagnosics, allergology and allergodiagnosics.
- Symposium on primary immunodeficiency “J Project”.
- Competition of young scientists for the best work in the field of immunology and allergology (oral and poster presentations).
- Exhibition of domestic and foreign companies.
- The cultural programme.

The Chairmen of the Conference Organizing Committee:

Chereshnev Valery, Academician of the Russian Academy of Sciences, President of RSI and the Ural Society of Immunologists, Allergologists and Immunorehabilitologists, member of the Presidium of the Ural Branch of the Russian Academy of Sciences, Director of the Institute of Immunology and Physiology of the Ural Branch of the Russian Academy of Sciences (Yekaterinburg).

Volchegonsky Ilya, Honored Scientist of the Russian Federation, Doctor of Medical Sciences, Professor, Rector of the South Ural State Medical University (Chelyabinsk).

Dolgushin Ilya, Academician of the Russian Academy of Sciences, Honored Scientist of Russia, Doctor of Medicine, Professor, President of the South Ural State Medical University (Chelyabinsk).

The Conference Secretariat:

Smagina Marina - coordinator of organizational issues of the conference
E-mail: san_2006@bk.ru

Chetvermina Elena - coordinator of the conference materials publications
E-mail: umm.ural2017@mail.ru



Monument to Russian composer Sergei Prokofiev in Chelyabinsk



The Monument to the Founders of Chelyabinsk

SUMMARY

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



L–R: A. Pishchalnikov (Chelyabinsk), A. Shcherbina (Moscow), I. Tuzankina (Yekaterinburg) L. Maródi (Budapest), S. Deryabina (Yekaterinburg), M. Bolkov (Yekaterinburg), M. Dolgikh (Yekaterinburg)

*MOMENTS OF THE MEETING...
AND THE AFTERPARTIES*



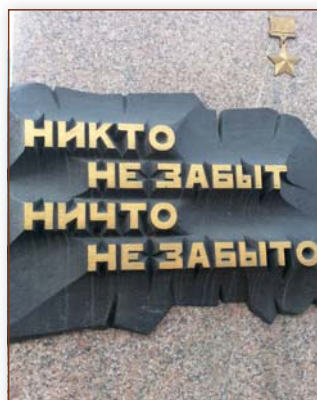
Ksenia Abramovskih, medical student, and László Maródi



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

Hosts: Mariana Murdjeva, Marta Baleva
Venue: Grand Hotel, Plovdiv
Main Topic: Rare diseases in immunology

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



Marta Baleva and Mariana Murdjeva



Snezhina Mihaylova



Mariana Murdjeva

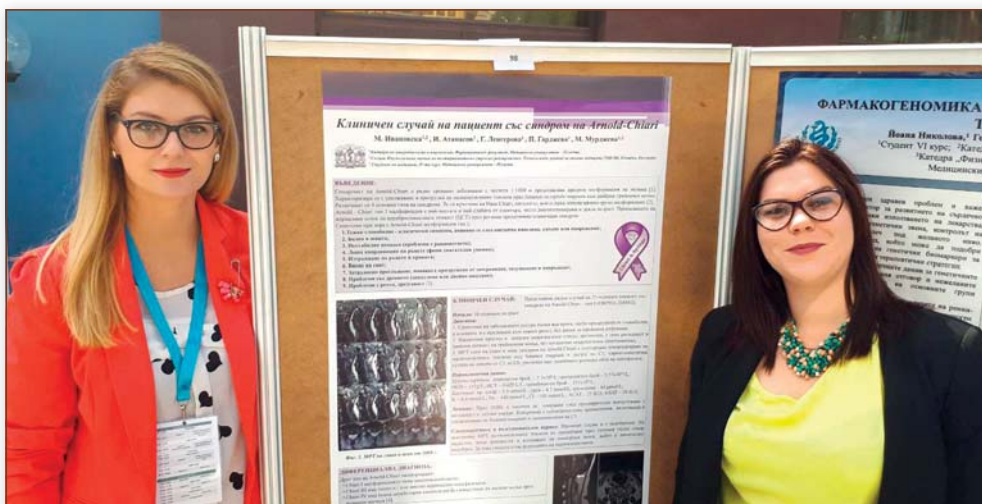
SUMMARY

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 Bal-eva* 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
Mariana Murdjeva*



Mariya Ivanovska and Gergana Lengerova

Hosts: László Maródi, Katalin Vámos
Venue: Edinburgh International Conference Center (EICC)
Main Topic: 9th J Project Steering Committee Meeting

PROGRAM

Welcome

Katalin Vámos (Budapest)

JP Booklet 2016

JP Meetings 2017

New JP countries

CIS Meeting, Boston

Ludwik Hirszföld 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 **R**are **I**mmunodeficiency, **a**uto**I**nflammatory, and **A**utoimmune 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 PIDs 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 misconduct 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.



The entrance of EICC

- 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 Maródi. 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 Maródi 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 heterogeneous 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

Hosts: Árpád Lányi, László Maródi
Venue: Clubhouse of the Foundation for Hungarian Rheumatology
Main Topic: Joint meeting with the Hungarian Society for PID (HSPID)

PROGRAM

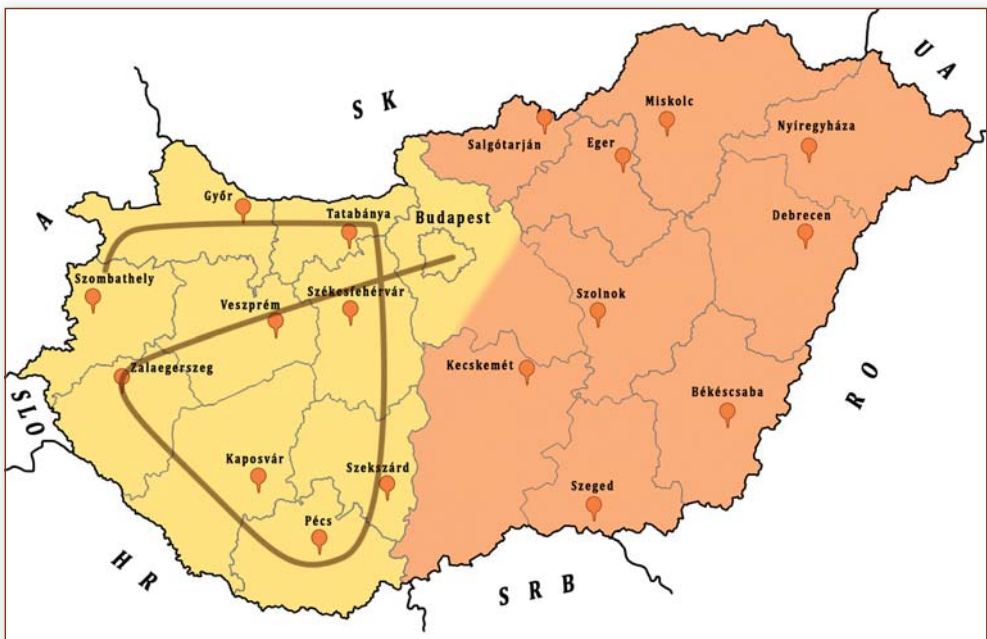
1. ESID Registry – The current state of reporting Hungarian patients to the ESID Registry
Beáta Tóth (Debrecen)
2. Current state of PID genetic diagnostics in Hungary: Perspectives of WGS and WES
Beáta Tóth (Debrecen)
3. The JP WEST-Hungary physician education program
László Maródi (Budapest)
4. The 3rd JP Congress: Participation of doctors, scientists and patients from Hungary
László Maródi (Budapest)
5. Report on the 17. ESID Congress in Edinburgh, 2017. September 10–14
László Maródi (Budapest)
6. Membership and financial issues in HSPID
Árpád Lányi (Debrecen)
7. Society events in 2017–2018
Árpád Lányi (Debrecen)

SUMMARY

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 realisation 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: Tatabánya, Győr, Szombathely, Zalaegerszeg, Veszprém, Székesfehérvár, Kaposvár, Pécs, Szekszárd. In addition, PID awareness events should be organized in different institutions in Budapest

Host: Elena Kovzel
Venue: Ritz Carlton Hotel, Astana City
Main Topic: Actual Issues of Clinical Immunology

PROGRAM

October 6

Press conference with participation of:

Birtanov YA, Maródi L, Prodeus AP, Belevtseva 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)



Astana
October 6, 2017



J-project	Lazlo Marodi
Kazakhstan	Kovzel Elena
Uzbekistan	Ismailova Adolat
Kyrgyzstan	Motusheva Raushan Dgzinibekova Cholpon
Tajikistan	Dodova Soliha Hodzaeva Nigzan Davlatova Madina






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 practicing 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

Kusherova 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 hypersensitivity"

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

SUMMARY

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 Zeynullovi 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).



*L: László Maródi (Hungary)
R: Andrey Prodeus (Russia)*

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



J CENTRAL ASIA DAUGHTERS PROJECT MEETING

*Davlatova Madina (Tajikistan); Dodova Salikha (Tajikistan); Khojaeva Nikzan (Tajikistan);
László Maródi (Hungary); Elena Kovzel (Kazakhstan);
Oxana Usenjva (Kazakhstan); Dzhienbekova Cholpon (Kyrgyzstan);
Svetlana Tyurina (Kazakhstan); Ismailova Adolat (Uzbekistan).*



*L–R: M Belevtsev, E Kovzel,
L Maródi*



*Tatiana Uglova (Belarus); Zhanat Ispayeva (Kazakhstan); László Maródi (Hungary); Elena Kovzel (Kazakhstan);
Minira Bulegeniva (Kazakhstan); Lazat Manzhuova (Kazakhstan); Svetlana Begimova (Kazakhstan).*

Hosts: Anna Sediva, Jiri Litzman
Venue: Clarion Congress Hotel, Olomouc
Main Topic: Primary immunodeficiencies and pulmonary involvement

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, diagnosis 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



*The Meeting Venue:
Clarion Congress Hotel, Olomouc*

R Zachova – STAT3GOF

T Milota – CVID Tly

Z Chovancova – CVID neutrophils

T Freiburger – HEA

E Hlavackova – rare immunodeficiencies

M Svaton – NGS



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.



The Town Hall of Olomouc

Anna Sediva, Jiri Litzman

Host: Ismail Reisli
Venue: Van Ticaret ve Sanayi Odasi, Van
Main Topic: Diagnosis and Treatment of Primary Immunodeficiency

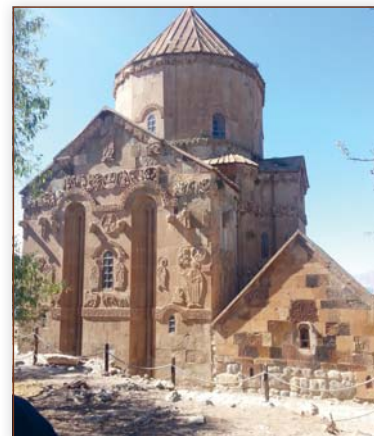
PROGRAM

   		
VAN J PROJECT MEETING Primer İmmün Yetmezlik (PIY) Tanı ve Tedavisi Diagnosis and Treatment of Primary Immunodeficiency (PID)		
Düzenleme Kurulu (Organization) Prof. Dr. Ismail Reisli Necmettin Erbakan University Prof. Dr. Zafar Çalıskamen Necmettin Erbakan University Prof. Dr. Ögüz Tuncer Yüzüncü Yıl University Communication Prof. Dr. Ismail Reisli Necmettin Erbakan University Muratlı Medical School Pediatric Immunology and Allergy 43080, KÖRÜŞ Tel: +91 352 223 66 90 Hno: 352 344 55 11 19 Ekim (October 13 th), 2017 18.00 – 20.00 Van Ticaret ve Sanayi Odası VAN, TÜRKİYE	Başkanlar/Chairs	
	18.00 – 18.15	Prof. Dursun Odabaş, Prof. Ögüz Tuncer
	18.15 – 18.30	AÇILIŞ (Opening) Prof. Dr. Dursun ODABAŞ Prof. Dr. Ögüz TUNCER
	18.30 – 18.45	Farkında mıyız? (PID Awareness) Prof. Dr. Ismail REİSLİ
	18.45 – 19.00	PIY Bulguları (Symptoms & Findings) Prof. Dr. Sevgi Keleş
	19.00 – 19.15	PIY Tedavisi (Treatment) Doç. Dr. Şakir Nail Güner
	19.15 – 19.45	Yetişkin Çağda PIY (PID in Adults) Prof. Dr. A. Zafar ÇALIŞKANER
	19.45 – 20.00	The widening scope of PID in children and adults Prof. Dr. László Maródi
	20.00	TARTIŞMA VE KAPANIŞ (Discussion)
	20.00	AKŞAM YEMEĞİ – ERKOC ÇAD KEBAP (DINNER) <small>Ticaret ve Sanayi Odası tarafından organize edilmiştir.</small>

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



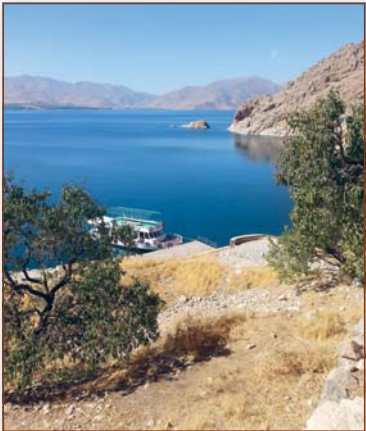
Holy Cross Church on Akhtamar Island

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



Organizers and sponsors of the Van J Project Meeting



Lake Van



Ismail Reisli



Zafer Çalışkaner



László Maródi



The audience



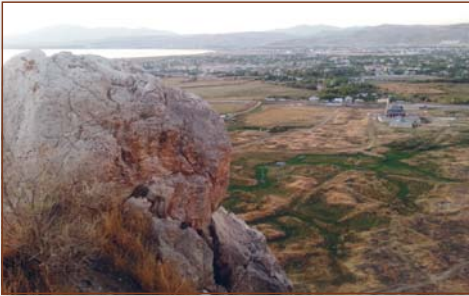
L–R: L Maródi, Z Çalışkaner, I Reisli



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



Speakers' dinner at Erkoç Restaurant



View from Van Castle



Views from Akhtamar Island



At the House of Van Cat



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



*Van Castle. L–R: Z Çalışkaner, I
L Maródi, and D Odabaş*

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 Chisinau

Svetlana Sciuca



*Lecture room
of the State University of Medicine and Pharmacy “Nicolae Testemitanu”*

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 Kiriak (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)

Diahreea 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 Presidium of the Meeting



Pediatricians and immunologists learning about PID at the J Project Meeting

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 to 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



Svetlana Sciuca at work



Visiting the Mother and Child Institute and discussion of clinical cases with complex PIDs Center, László Maródi and Svetlana Sciuca, right, Valentin Țurea with residents and students.

Hosts: Irina Kondratenko, Yuri Smolkin, Andrey Bologov
Venue: Moscow Holiday Inn, Moscow
Main Topic: Allergy and immunodeficiency

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



Moscow Holiday Inn: the meeting venue



The hospital building complex



Irina Kondratenko serving cake for children

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 socioeconomic 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 established PID care in Kosovo.

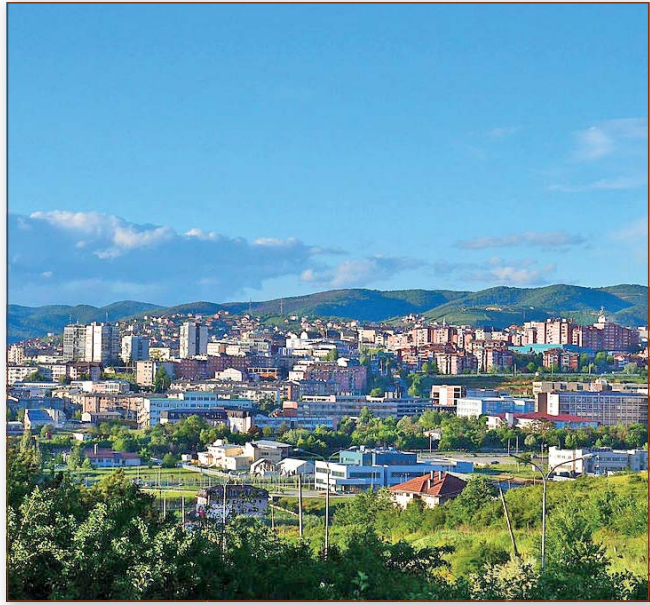
Vlora Ismaili-Jaha



Georghina Kuli-Lito (middle) chairing the session



The Clock Tower in Pristina



View of Pristina



The Meeting Room in Hotel Emerald

J Project Meetings 2004–2017

City (Country)	Organizer	Date
2004		
1. Targu Mures, Romania	Csilla Todea	March 11–12
2. Prague, Czech Republic	Anna Sediva	May 10–11
3. Belgrade, Serbia/Montenegro	Srdjan Pasic	June 11–12
4. Skopje, Macedonia	Katarina Stavrik	September 17–18
5. Kyiv, Ukraine	Alla Volokha	November 18–19
6. Zakopane, Poland	Ewa Bernatowska	December 16–17
2005		
7. Sofia, Bulgaria	Elissaveta Naumova	April 15–16
8. Prague, Czech Republic	Anna Sediva	May 9–10
9. Gdansk, Poland	Ewa Bernatowska	September 23–24
10. Debrecen, Hungary	László Maródi	November 4–5
11. Lviv, Ukraine	Larysa Kostyuchenko	November 25
12. Oradea, Romania	Zoltan Ellenés	December 20
2006		
13. Debrecen, Hungary	László Maródi	January 16
14. Prague, Czech Republic	Anna Sediva	May 8–9
15. Bucharest, Romania	Nicolae Iagaru	June 9–10
16. Minsk, Belarus	Michael Belevtsev	November 9–10
17. Debrecen, Hungary	László Maródi	December 8–9
2007		
18. Zaporozhzhie, Ukraine	Lyudmila Chernyshova	Apr 19–20
19. St. Petersburg, Russia	Marina Guseva	May 29–30
20. Ohrid, Macedonia	Kristina Mironska	September 20–21
21. Iasi, Romania	Aurica Rugina	October 12–13
22. Ljubljana, Slovenia	Tadej Avcin	November 16–17
2008		
23. Odessa, Ukraine	Lyudmila Chernyshova	April 10
24. Sunny Beach, Bulgaria	Elissaveta Naumova	May 22–23
25. Sarajevo, Bosnia-Herzegovina	Velma Mulaosmanovic	October 10–11
26. Chisinau, Rep. of Moldova	Lyudmila Cerempei	October 31– November 1
27. Riga, Latvia	Tatjana Prokofjeva	November 27–28

2009

28.	Timishoara, Romania	Margit Serban	March 19–20
29.	Sevastopol, Ukraine	Liudmyla Chernyshova	April 9–10
30.	Yekaterinburg, Russia	Irina Tuzankina	May 13–14
31.	St. Petersburg, Russia	Marina Guseva	June 9–10 2009
32.	Konya, Turkey	Ismail Reisli	June 25–26
33.	Krakow, Poland	Danuta Kowalczyk	September 24–25
34.	Tallinn, Estonia	Sirje Velbri	October 7–8
35.	Ljubljana, Slovenia	Nataša Toplak	October 9–10
36.	Tehran, Iran	Asghar Aghamohammadi & Nina Rezaei	October 11–12
37.	Cairo, Egypt	Nermeen Galal	October 18–19
38.	Minsk, Belarus	Michael Belevtsev	October 22–23

2010

39.	Tirana, Albania	Gerorgina Kuli-Lito	April 8–9
40.	Porto Marina, Egypt	Aisha El-Marsafy	April 16–17
41.	Kharkov, Ukraine	Liudmyla Chernyshova	May 19–20
42.	Zlatibor, Serbia	Srdjan Pasic	June 1–2
43.	Zagreb, Croatia	Darko Richter	July 2–3
44.	Chelyabinsk, Russia	Irina Tuzankina	August 30–31
45.	Budapest, Hungary 1th J Project Steering Committee Meeting	László Maródi. & Miklós Szolnok	September 9–10
46.	Tehran, Iran	Asghar Aghamohammadi & Nima Rezaei	October 11–12

2011

47.	Pushkin Hills, Russia & AregTotolian	Marina Guseva	February 3–4
48.	Zakopane, Poland	Ewa Bernatowska	February 24–26
49.	Oradea, Romania	Ladislau Ritli	March 1, 2011
50.	Debrecen, Hungary 2nd J Project Steering Committee Meeting	László Maródi 50th J Project Meeting – Celebration	March 10–11
51.	Moscow, Russia	Irina Kondratenko	March 31–April 1
52.	Baku, Azerbaijan	Gulnara Nasrullayeva	April 22–23
53.	Bratislava, Slovakia	Peter Ciznar	April 28–29
54.	Lutsk, Ukraine	Liudmyla Chernyshova	May 11–12
55.	Sibiu, Romania	Sorin Iurian	June 10–11
56.	Chelyabinsk, Russia	Irina Tuzankina	June 26–27
	J Project session Beijing, China	Tina Lee	September 23
57.	Ohrid, Rep. Macedonia	Kristina Mironska	October 8
58.	Tehran, Iran	Nima Rezaei	October 15
59.	Trabzon, Turkey	Fazil Orhan & Ismail Reisli	November 19–20
60.	Riga, Latvia	Tatjana Prokofjeva	November 26

2012

61.	Lillafüred, Hungary	Miklós Szolnoky	January 20–21
62.	Budapest, Hungary 3rd J Project Steering Committee Meeting	Miklós Szolnoky & Judit Szabó	January 27–28
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 & Nima Rezaei	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 & Anna Sediva	May 31
91.	Budapest, Hungary 4th J Project Steering Committee Meeting	László Maródi	May 31–June 1
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

2014

99. Pushkin Hills, Russia	Areg Totolian & Marina Guseva	February 5
100. Antalya, Turkey 1st J Project Congress 5th J Project Steering Committee Meeting	László Maródi & Ismail Reisli 100th J Project Meeting - Declaration	March 12–14
101. Antalya, Turkey	Ismail Reisli	March 15
102. Zagazig, Egypt	Mohamed Almaky	April 17
103. Tehran, Iran	Nima Rezaei & Asghar Aghamohammadi	April 22–29
104. Poltava, Ukraine	Liudmyla Chernyshova	April 24–25
105. Bratislava, Slovakia	Peter Ciznar	April 25
106. Debrecen, Hungary	László Maródi	April 26
107. St. Petersburg, Russia	Tatiana Nasyrina	May 28
108. Varna, Bulgaria	Elissaveta Naumova	October 6
109. Catez, Slovenia	Tadej Avčin	October 11–12
110. Tehran, Iran	Nima Rezaei	October 18–19
111. Yekaterinburg, Russia	Irina Tuzankina	October 24–25
112. Warsaw, Poland	Ewa Bernatowska	October 24–25
113. Pardubice, Czech Republic	Anna Sediva	November 11
114. Nizhny Novgorod, Russia	Tatiana Nasyrina	November 26
115. Sibiu, Romania	Sorin Iurian	November 27–28
116. Erzurum, Turkey	Dilara Kocacik Uygun & Demet Hafizoğlu	December 6
117. Chisinau, Moldova	Liudmila Cerempei	December 12

2015

118. Moscow, Russia	Irina Kondratenko	February 18–19
119. Budapest, Hungary 6th J Project Steering Committee Meeting	László Maródi	March 5–6
120. Bratislava, Slovakia	Peter Ciznar	April 21–22
121. Tehran, Iran	Nima Rezaei	April 22–23
122. Minsk, Belarus	Mikhail Belevtsev	April 23–24
123. Debrecen, Hungary	László Maródi	April 25–26
124. Antalya, Turkey	Ismail Reisli	April 29
125. Oryol, Russia	Irina Snimshehikova	May 14–15
126. Sakarya, Turkey	Ismail Reisli	May 17
127. Zhytomyr, Ukraine	Liudmyla Chernyshova	May 21–22
128. Dolenjske Toplice, Slovenia	Tadey Avcin	May 22–23
129. St. Petersburg, Russia	Marina Guseva	June 3–4
130. Perm, Russia	Irina Tuzankina	July 2–3
131. Timisoara, Romania	Margit Serban	September 3–4
132. Tehran, Iran	Nima Rezaei	October 8–9
133. Tirana, Albania	Georgina Kuli-Lito	November 20–21

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	László Maródi & Ismail Reisli	March 2–5
139. Tehran, Iran	Nima Rezaei & Ashgar Agamohammadi	April 23–24
140. Bratislava, Slovakia	Peter Ciznar	April 27
141. Kaunas, Lithuania	Brigita Sitkauskienė	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 & Jiri Litzman	October 12
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	László Maródi, & Katalin Vámos	March 2–3
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	Brigita Sitkauskienė	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	László Maródi & Katalin Vámos	September 12
164. Budapest, Hungary	László Maródi	September 22
165. Astana City, Kazakhstan	Elena Kovzel	October 6–7
166. Olomouc, Czech Republic	Anna Sediva	October 10

167. Van, Turkey	Ismail Reisli	October 13–14
168. Chisinau, Rep. of Moldova	Svetlana Sciuca	November 3
169. Moscow, Russia	Irina Kondratenko	November 24
170. Pristina, Kosovo	Vlora Ismaili-Jaha	December 16

Number of JP Meetings between 2004–2017: 170

J Project Meetings 2018

Meeting venue	Organizer(s)	Schedule
171. Budapest, Hungary (JP SC)	László Maródi & Katalin Vámos	March 9–10
172. Konya, Turkey	Ismail Reisli	March 20
173. Bratislava, Slovakia	Peter Ciznar	April 10–11
174. St. Petersburg, Russia	Marina Guseva	April 4
175. Minsk, Belarus	Michael Belevtsev	April 19–20
176. Tehran, Iran	Nima Rezaei	April 21–23
177. Kiev, Ukraine	Liudmyla Chernishova & Alla Volokha	April 26–27
178. Almaty, Kazakhstan	Zhanat Ispayeva	April 27
179. Kaunas, Lithuania	Brigita Sitkauskienė	May 2
180. Batman, Turkey	Ismail Reisli	May 3
181. Warsaw, Poland	Ewa Bernatowska	May 10–11
182. Ljubljana, Slovenia	Tadej Avcin	May 12
183. Skopje, Rep. Macedonia	Kristina Mironska	May 18
184. Astana City, Kazakhstan	Elena Kovzel	June 9
185. Tsigov Chark, Bulgaria	Elissaveta Naumova & Mariana Murdjeva	June 15–17
186. Chisinau, Rep. Moldova	Svetlana Sciuca	June
187. Ekaterinburg, Russia	Irina Tuzankina	Sep 18
188. Uzbekistan, Tashkent	Diloram Musahodzhayeva, Irina Tuzankina	Sep 24
189. Uzbekistan, Bukhara	Diloram Musahodzhayeva, Irina Tuzankina	Sep 26
190. Pristina, Kosovo	Vlora Ismaili-Jaha	Sep
191. Urfa, Turkey	Ismail Reisli	Oct 5–6
192. Brno, Czech Republic	Anna Sediva	Oct 10
193. Lisbon, Portugal (JP SC)	László Maródi & Katalin Vámos	Oct 25
194. Tirana, Albania	Georgina Kuli-Lito	Dec
195. Sofia, Bulgaria	Elissaveta Naumova & M Nikolova	Oct
196. Tbilisi, Georgia	Karaman Pagava	Oct 27–28
197. Dushanbe, Tajikistan	Kosimov Abduloevich	Nov
198. Sarajevo, Bosnia&H	Velma Mulaosmanovic	Nov
199. Herceghalom, Hungary	Laszlo Marodi, Katalin Vamos	Nov

J Project Steering Committee Meetings

Year	Date	City	Venue
1. 2010	Sep 10–11	Budapest	Hotel Ramada
2. 2011	Mar 10–11	Debrecen	Hotel Thermal Aquaticum
<i>At the 50th J Project Meeting – Celebration</i>			
3. 2012	Jan 27–28	Budapest	Hotel Mercure Korona
4. 2013	May 31–Jun 1	Budapest	Grand Hotel Margitsziget
5. 2014	Mar 12–14	Antalya	Hotel Rixos Lares
<i>At the 100th J Project Meeting – Declaration</i>			
6. 2015	Mar 5–6	Budapest	Grand Hotel Margitsziget
7. 2016	Mar 2	Antalya	Hotel Sherwood
8. 2017	Mar 2–3	Budapest	Hotel Flamenco
9. 2017	Sep 18	Edinburgh	Congress Center

J Project Executive Committee Meeting

Year	Date	City	Venue
2016	Sep 23	Barcelona	Congress Center

The J Project Steering Committee

Name E-mail	City	Country
1. Georgina KULI-LITO <i>gkuli_lito@hotmail.com</i>	ALBANIA	Tirana
2. Gulnara NASRULLAYEVA <i>g.nasrullayeva@hotmail.com</i>	AZERBAIJAN	Baku
3. Michail BELEVTSSEV <i>belevtsev_m@mail.ru</i>	BELARUS	Minsk
4. Svetlana SHARAPOVA <i>sharapovasv@gmail.com</i>	BELARUS	Minsk
5. Velma SELMANOVICH <i>velmamulaosmanovic@hotmail.com</i>	B&H	Sarajevo
6. Elissaveta NAUMOVA <i>naumovaej@gmail.com</i>	BULGARIA	Sofia
7. Jadranka KELECIC <i>jkelecic17@gmail.com</i>	CROATIA	Zagreb
8. Anna SEDIVA <i>AnnaSediva@fnmotol.cz</i>	CZECH REP.	Prague
9. Jiri LITZMAN <i>jiri.litzman@fnusa.cz</i>	CZECH REP.	Brno

10. Aisha EL-MARSAFY <i>aisha_mars@hotmail.com</i>	EGYPT	Cairo
11. Nermeen GALAL <i>nermeengalal@gmail.com</i>	EGYPT	Cairo
12. Sirje VELBRI <i>velbrisir@hotmail.com</i>	ESTONIA	Tallinn
13. Krista RESS <i>krista.ress@gmail.com</i>	ESTONIA	Tallinn
14. László MARÓDI <i>laszlo.marodi@med.semmelweis-univ.hu</i>	HUNGARY	Debrecen
15. Melinda ERDŐS <i>melinda.erdos@yahoo.com</i>	HUNGARY	Debrecen
16. Katalin VÁMOS <i>kvamos@convention.hu</i>	HUNGARY	Budapest
17. Asghar AGHAMOHAMMADI <i>aghamohammadi@Tums.ac.ir</i>	IRAN	Tehran
18. Nima RESAEI <i>rezaei_nima@yahoo.com</i>	IRAN	Tehran
19. Hassan ABOLHASSANI <i>abolhassanih@yahoo.com</i>	IRAN	Tehran
20. Elena KOVZEL <i>elenakovzel@inbox.ru</i>	KAZAHSTAN	Astana City
21. Vlora ISMAILI-YAHA <i>vlorajaha@yahoo.com</i>	KOSOVO	Prishtin
22. Tatjana PROKOFJEVA <i>monja@balticom.lv</i>	LATVIA	Riga
23. Brigita SITKAUSKIENE <i>brigita.sitkauskiene@kaunoklinikos.lt</i>	LITHUANIA	Kaunas
24. Ewa BERNATOWSKA <i>bernatoswskae@yahoo.com</i>	POLAND	Warsaw
25. Malgorzata PAC <i>malgorzata.pac@wp.pl</i>	POLAND	Warsaw
26. Malgorzata SKOMSKA <i>malgosia.skomska@gmail.com</i>	POLAND	Krakow
27. Kristina MIRONSKA <i>mironska2002@yahoo.com</i>	MACEDONIA	Skopje
28. Svetlana SCIUCA <i>ssciuca@yahoo.com</i>	MOLDOVA	Chisinau
29. Margit SERBAN <i>mserban@rdstm.ro</i>	ROMANIA	Timishoara
30. Mihaela BATANEANT <i>mihabataneant@yahoo.com</i>	ROMANIA	Timishoara
31. Alexander PISHCHALNIKOV <i>pau6277@yandex.ru</i>	RUSSIA	Chelyabinsk
32. Irina KONDRATENKO <i>ikondratenko@rambler.ru</i>	RUSSIA	Moscow

33. Marina GUSEVA <i>gusevamarina@mail.ru</i>	RUSSIA	St. Petersburg
34. Irina TUZANKINA <i>ituzan@yandex.ru</i>	RUSSIA	Yekaterinburg
35. Srdjan PASIC <i>Pasics@ikomline.net</i>	SERBIA	Beograd
36. Peter CIZNAR <i>ciznar@dfnsp.sk</i>	SLOVAKIA	Bratislava
37. Tadej AVCIN <i>tadej.avcin@siol.net</i>	SLOVENIA	Ljubljana
38. Gasper MARKELJ <i>gasper.markelj@kclj.si</i>	SLOVENIA	Ljubljana
39. Kosimov ABDULOEVICH <i>doctor-kosimov@mail.ru</i>	TAJIKISTAN	Dushanbe
40. Ismail REISLI <i>ireisli@hotmail.com</i>	TURKEY	Konya
41. Zafer CALISKANER <i>caliskaner@yahoo.com</i>	TURKEY	Konya
42. Liudmyla CHERNYSHOVA <i>chernyshova@ukr.net</i>	UKRAINE	Kyiv
43. Anastasia BONDARENKO <i>nastyabond@bk.ru</i>	UKRAINE	Kyiv
44. Alla VOLOKHA <i>volokha@gmail.com</i>	UKRAINE	Kyiv
45. Larysa KOSTYUCHENKO <i>lkostyuchenko@ukr.net</i>	UKRAINE	Lviv
46. Ihor SAVCHAK <i>doktorsavchak@gmail.com</i>	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 Sitkauskienė	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>

ISSN 2064-1184

Printed by Alföldi Nyomda Zrt.