

THE J PROJECT



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ECE IPI CTR

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Contents

Foreword	3
ECE IPI CTR	4
J Project Meetings in 2012	5
Lillafüred	6
Budapest	7
Rostov-on-Don	10
Moscow	11
Chernihiv	13
Tallinn	15
Tehran	16
Bratislava	17
Diyarbakir	18
Prague	20
Konya	22
Warsaw	24
Sibiu	26
Tzigov Chark	28
Astana City	30
Tyumen	31
Ljubljana	32
Tehran	33
Timisoara	35
Minsk	37
Ufa	39
Sanliurfa	40
Cracow	41
J Project Meetings in 2004–2012	42
Scheduled J Project Meetings in 2013	44
J Project Steering Committee Members	45
Genetic testing at the Debrecen PID Reference Center	46

Foreword

As always, it gives me great pleasure to review recent achievements and events of the J Project over the past year. Having organized 83 meetings until the end of 2012 indicates the dynamics and professional appreciation of the Project. It is amazing that we are approaching the 100th J Project Meeting which we are very much looking forward to and will celebrate accordingly. Perhaps the most important of all events last year was that new branches of the Project have been established which we refer to as the **J Daughters Project (JDP)**. This alone indicates that the J Project concept and spirit is spreading to where there is a need. The JDP was formulated by clinicians and scientists working in the primary immunodeficiency (PID) field in various areas of Western Asia. The JDP has the same structure and concept as the J Project physician education and research collaboration program and is run by local leaders who are worldwide known clinical immunologists of established PID centers. The major aims of the JDP were formulated as follows: 1) to identify more patients with PIDs in early life; 2) to expand the J Project concept and spirit to new areas with low number of diagnosed and treated PID patients; 3) to develop new PID centers for genetic testing of innate errors of immunity; 4) to promote organization of awareness meetings and activities in Central and Eastern *Turkey (J Anatolia Project, JAP)*, *Iran (J Persia Project, JPP)*, *Kazakhstan (J Central-Asia Project, JCAP)*, and in the *Urals region* of Russia (**J Siberia Project, JSP**). Considering the current number of diagnosed and appropriately treated PID patients the major aims of these projects are to increase awareness, education and innovation in order that Western Asia will reach milestones as Eastern and Central Europe did by the J Project. Sharing local and international experience and introducing new initiatives will be critically important in Central Asian countries including *Kazakhstan, Uzbekistan, Turkmenistan, Tajikistan, and Kirgyzstan*. For the JDP to be a success, it is necessary to develop a permanent collaboration with the ongoing J Project programs and international societies like the European Society for Immunodeficiencies and charity organizations like the Jeffrey Modell Foundation, as well as pharmaceutical companies. Established local support from the respective governments and institutions should be obtained by each center. Organized educational programs and facilities, and developing PID diagnostic centers and genetics laboratories are of utmost importance. Since genetic diagnostics is indispensable for the definitive diagnosis including prenatal and early neonatal diagnosis of PIDs it is the major interest of the JDP centers to set up and equip established immunological laboratories capable to offer genetic testing for PIDs in their regions. We are grateful to Biotest Hungaria Kft and Biotest GmbH and Octapharma Nordic AB for their ongoing and generous support which has allowed us to run the J Project and in particular for sponsorship of genetic testing of PID patients from all over ECE in the Debrecen PID Genetics Laboratory.

Debrecen, December, 2012

László Maródi



University of Debrecen Medical and Health Science Center

The **Eastern and Central European Infectious and Pediatric Immunology Center for Training and Research (ECE IPI CTR)** was established on December 22, 1999. From educational and scientific points of view, the Center is closely associated with the **Department of Infectious and Pediatric Immunology** at the **University of Debrecen Medical and Health Science Center**. The Department has a strong profile of immunology including research into antimicrobial host defense mechanisms. The main fields of research activity of the Department are as follows:

- Molecular pathology of primary immune deficiency diseases
- Host defense mechanisms against bacteria and fungi
- Mechanisms of action of intravenous immunoglobulin
- Developmental biology of macrophages

The Center provides modern educational utilities, demonstrational materials, and rooms that are suitable for practical seminars as well as a lecture rooms. ECE IPI CTR functions as an institutional and regional infectious and pediatric immunology center. Its essential role is the initiation of regular postgraduate courses for specialists in infectious diseases and immunology in countries of Eastern Europe.

From the conception aspects, ECE IPI CTR is tightly connected with the **Interregional Association of the Carpathian Euro-region**, one of the main aims and functions of which is the formulation of educational and scientific co-operation within the region of Eastern and Central Europe.

PID Awareness Meetings in 2012

City (Country)	Date
1. Lillafüred (<i>Hungary</i>)	January 20–21
2. Budapest (<i>Hungary</i>)	January 27–28
3. Rostov-on-Don (<i>Russia</i>)	March 16
4. Moscow (<i>Russia</i>)	March 29
5. Chernihiv (<i>Ukraine</i>)	April 5–6
6. Tallinn (<i>Estonia</i>)	April 19
7. Tehran (<i>Iran</i>)	April 22
8. Bratislava (<i>Slovakia</i>)	April 27
9. Diyarbakir (<i>Turkey</i>)	May 12
10. Prague (<i>Czech Republic</i>)	May 14–15
11. Konya (<i>Turkey</i>)	May 26–27
12. Warsaw (<i>Poland</i>)	June 1–2
13. Sibiu (<i>Romania</i>)	June 2
14. Tzigov Chark (<i>Bulgaria</i>)	June 8–9
15. Astana City (<i>Kazakhstan</i>)	June 12–15
16. Tyumen (<i>Russia-Siberia</i>)	July 2
17. Ljubljana (<i>Slovenia</i>)	September 14–15
18. Tehran (<i>Iran</i>)	October 13–14
19. Timisoara (<i>Romania</i>)	October 25–26
20. Minsk (<i>Belarus</i>)	November 17
21. Ufa (<i>Russia</i>)	November 23
22. Sanliurfa (<i>Turkey</i>)	November 25
23. Cracow (<i>Poland</i>)	December 15

Aims

1. To organize professional meetings on PIDs and related diseases in regions of Eastern and Central European countries with low number of registered PID patients.
2. To discuss diagnostic and therapeutic practices and problems, and to define specific areas to be improved and to be supported by other European groups, institutions, companies, and foundations.
3. Updating national PID registries.
4. Establishing PID professional working groups.
5. Establishing PID patients' groups.

Structure of the Meetings

1. Informal discussion on the day before the meeting.
2. Introductory lectures by invited and local speakers.
3. Case reports mostly by local speakers.
4. PID WG and patients' group activity in the country.
5. National registry update.

Host: Miklós Szolnoky (*szolnoky.miklos@biotest.hu*)

Venue: Hotel Palota

Main Topic: Meeting of the Hungarian Pediatric Immunology Working Group

PROGRAM

January 20

Immunodeficiency in adults

Brúgós, B. (Hungary)

Clinical characteristics of adult immunodeficient patients

Sütő, G. (Hungary)

Secondary immunodeficiency in adults

Szántó, A. (Hungary)

CVID – Patients followed in the Szent László Hospital

Kriván, G., Goda, V. (Hungary)

Primary antibody deficiency with bronchiectasia

Szolnoky, M., Kriván, G., Goda, V., Kalmár, Á. (Hungary)

The laboratory diagnosis of CVID

Németh, J. (Hungary)

Clinical relevance of IgG subclass levels and comparative study of methods of measurement

Miklós, K., Szabó, Zs. (Hungary)

Autoimmunity in primary immunodeficiency

Zeher, M. (Hungary)

HIV infection and AIDS

Bánhegyi, D. (Hungary)

Complement system and infections

Füst, Gy. (Hungary)

January 21

Primary immunodeficiencies

Maródi, L. (Hungary)

Report on the J Project Steering Committee Meeting

Maródi, L. (Hungary)

Lung and bone marrow transplantation in chronic granulomatosis

Nagy, K. (Hungary)

Ocular complications of APS1

Dohán, J. (Hungary)

New therapeutical approaches to the treatment of HANO

Farkas, H. (Hungary)

Thrombotic microangiopathy

Prohászka, Z. (Hungary)

Molecular immunology of hyper-IgM syndrome

Dérfalvi, B., Kovács, L., Erdős, M., Maródi, L. (Hungary)

Incontinentia pigmenti

Csürke, I., Oroszlán, K., Kassay, A., Szabó, K., Merő, G., Dicső, F. (Hungary)

Autoimmune polyendocrine disease type 1 – case report

Dohán, J., Tóth, B., Maródi, L. (Hungary)

Glucose-6-phosphate metabolism disorders in congenital neutropenia

Kardon, T., Pittner, R., Száraz, P., Krämer, S., Kriván, G. (Hungary)

An unusual case of neutropenia

Mosdósi, B., Nyul, Z., Ottóffy, G., Adonyi, M., Maródi, L. (Hungary)

SUMMARY AND CONCLUSION

The scientific meeting of the Pediatric Immunology Working Group (WG) was held at Hotel Palota, in Lillafüred from 20th to 21st January 2012. This WG was established in 1985. It had had annual scientific meetings; this time the conference was also designated as one of the J Project Meetings. Immunodeficiency in adults was one of the main topics and colleagues treating adult patients were invited. Autoimmunity in primary immunodeficiency was in the focus of the symposium. Laboratory diagnostic difficulties and complications of PIDs, like bronchiectasia, were discussed. Presentations on secondary and acquired immunodeficiency were also included in addition to the functioning of the complement system. Specialists from non-immunological fields including ophthalmologists also took part. Instructive case reports were presented. The WG members discussed future plans and activities in order to improve the level of PID care and registry in Hungary.

Miklós Szolnoky

*"I am sitting
here on a glittering wall of rocks.
The mellow wind of the young
summer
like the warmth of a good supper
flies around."*

Ode (Attila József)



BUDAPEST, HUNGARY

January 27–28, 2012

Host: László Maródi (*lmarodi@dote.hu*)

Venue: Hotel Mercure Budapest Korona

Main Topic: 2nd J Project Steering Committee Meeting

PROGRAM

January 27

Welcome

Knirsch, W. (Germany)

General introduction

Maródi, L. (Hungary)

Reports by PID center leaders

(All)

January 28

J Project registry (JPR) and awareness campaigns

Horváth, Zs., Maródi, L. (Hungary)

J Project journal

J Project clinical research projects

J Project meetings in non-ECE countries

El-Marshafy, A. (Egypt), Reisli, I. (Turkey), Rezaei, N. (Iran)

J Project meetings – 2012

Horváth, Zs. (Hungary)

J Project juniors' meeting – 2012

Knirsch, W. (Germany)

The J2 Project

Maródi, L. (Hungary)

Summary and Conclusion

Maródi, L. (Hungary)



Budapest

SUMMARY AND CONCLUSION

The J Project physician education campaign was started in 2004. The program involves more and more clinicians and researchers from year to year. The Steering Committee meeting in 2012 was organized in Budapest with thirty-eight physicians taking part. The J Project Registry, local working group activities, patients' groups and nursing groups were discussed at this Meeting. An agreement was concluded that a formal J Project registry was needed to follow up the number of patients diagnosed and treated in J Project countries. Participants of the SC Meeting also agreed that formal national PID working groups or societies, patients' groups, and nursing groups should be organized in each J Project country. The SC also agreed that running national PID registries are critically important as part of the awareness activities. It was announced that in order to better organize PID diagnostics, and to assure the treatment of as many PID patients as possible the Hungarian Organization for Patients with



*Participants
of the SC meeting*

Immunodeficiencies (HOPI) and the Hungarian Society for Immunodeficiencies (HUSID) had been established. Experiences with successful PID awareness activities in various J Project countries should be shared between national groups. Examples of some of these activities were introduced at this Meeting, like PID T-shirts from the Czech Republic, summer camps in Serbia, and PID sessions organized in county hospitals in Hungary or visits to Hungarian kindergartens and Baby-Mom clubs and churches.

Zsuzsa Horváth



Gulnara Nasrullayeva (Azerbaijan)



Georgina Kuli-Lito (Albania)



Ismail Reisli (Turkey)



Irina Kondratenko (Russia)



L–F: Kristina Mironska, Malgorzata Pac, Ewa Bernatowska, Nima Rezaei



L–F: Ismail Reisli, Nima Rezaei, László Maródi

Host: Tatiana Nasyrina (*Tatiana_nasyrina@concord.ru*)

Venue: Southern Federal District of Russian Federation-SFD

Main Topic: Primary immunodeficiencies: introduction to practice

PROGRAM

March 16

Film demonstration: *The Right to Life*

Adaptive and innate immunity in patients with agammaglobulinemia

Sizyakina, L. (Russia)

Primary immunodeficiencies. Diagnostic principles

Kondratenko, I. (Russia)

The modern concept of therapy of primary immunodeficiencies: Experience with IVIG Intratect

Latisheva, T. (Russia)

Th17 cells and host defense against candida

Maródi, L. (Hungary)

Frequently ill children: algorithm of diagnostics and therapy

Chagaeva, E. (Russia)

Local experience of diagnosis of PID

Lesik, D. (Russia)

Intravenous immunoglobulin preparations

Hasanov, U. (Russia)

Creation of PID patients' registers

Andreeva, I. (Russia)



L–R: Elena Latisheva, Tatiana Latisheva, László Maródi, Irina Kondratenko, Liudmila Sizyakina, Mikhail Zvidentsov

SUMMARY AND CONCLUSION

For the first time a one-day J Project meeting was held on the 16th of March, 2012, in Rostov-on-Don (Southern Federal District of Russian Federation-SFD). Rostov Region Ministry of Health, Southern-Russian regional center of Allergy and Clinical Immunology, Southern-Russian Department of Allergologist and Immunologist Association took part in the organization. Liudmila Sizyakina, chief allergist-immunologist of Southern Federal District and Rostov Region Ministry of Health, was the main

organizer of the meeting. One hundred and eighteen doctors (mostly immunologists and pediatricians) from different regions of SFD – from Rostov-on-Don, Krasnodar, Stavropol, Republics of Adygeya, Kabardino-Balkaria, Karachayevo-Cherkess, Kalmykia attended in the conference. The goal of the J Project Meeting in Rostov-on-Don called «Primary Immunodeficiency – Practice basics» was to discuss pressing diagnostic and therapeutic problems of patients with primary immunodeficiencies. Specialists from Moscow, Rostov-on-Don, Krasnodar and Hungary gave presentations. The meeting started with the showing of the popular science film «The right to life», which demonstrated key problems convincingly for patients with primary immunodeficiencies. Then Professor Irina Kondratenko gave a report on principles of PID diagnosis, emphasizing the necessity of early diagnosis of these defects. Professor Liudmila Sizyakina expanded on peculiarities of adaptive and innate immunity in patients with agammaglobulinemia. Professor Tatiana Latysheva expanded on the problem of primary immunodeficiency therapy. Professor László Maródi explained in lay language the role of Th17 cells in the formation of antifungal immunity. In the second part of the meeting, the creation of a patients’ register with PID in Rostov-on-Don was discussed. Doctor Dina Lesik from Krasnodar shared her clinical experience and positive results of diagnosis and treatment. The interest of the audience was attracted by the report about recurrent respiratory infections in children, who shouldn’t be applied to PID group. The doctors shared their experience in treating these patients. There were some citations for holding of such an informative meeting of chief doctors of North Caucasian hospitals, whose doctors took part in this meeting. The opening of several departments for PID treatment in SFD was the result of successful educational policy: one month after the J Project meeting in Rostov-on-Don a new department with 20 beds for PID patients was opened for the first time in the Regional Clinical Hospital N°2, and 2 months afterwards, a license for PID patients’ treatment was received in Krasnodar on at the Regional Clinical Children’s Hospital.

Tatiana Nasyrina

MOSCOW, RUSSIA

March 29, 2012

Host: Irina Kondratenko (*ikondratenko@rambler.ru*)

Venue: Russian Children’s Clinical Hospital

Main Topic: Educational meeting “Primary immunodeficiencies in pediatric practice”

PROGRAM

March 29

Interactions of cells in immune response
Yarilin, A. (Russia)

Evaluation of blood cell populations in clinical practice
Khaidukov, S. (Russia)

Classification of primary immunodeficiencies

Kondratenko, I. (Russia)

Combined T and B-cell immunodeficiencies: Predominantly antibody Deficiencies

Paschenko, O. E. (Russia)

Other well-defined immunodeficiency syndromes: Phagocytic defects

Deripapa, E. (Russia)

Diagnostic criteria and principles of therapy of PID

Kondratenko, I. (Russia)

Hereditary angioedema

Kapustina, A. (Russia)

Intravenous immunoglobulins: what and when?

Bologov, A. (Russia)

SUMMARY AND CONCLUSION

The J Project “Primary immunodeficiencies (PIDs) in pediatric practice” awareness meeting was held in Moscow, Russia on March 29, 2012. The meeting was organized by the Department of Clinical Immunology of Russian Children’s Clinical Hospital, Russian National Scientific Medical University in collaboration with the PID Care in Development Working party of the European Society for Immunodeficiencies. The meeting was attended by 95 participants (pediatricians and allergologists-immunologists from outpatient departments 28 – Moscow Region, 7 – Moscow and other regions of Russia, including St-Petersburg, Krasnodar) and 60 post-graduate students from Russian National Scientific Medical University. The J Project meeting in Moscow was devoted to “Primary immunodeficiencies in pediatric practice” with the aim to discuss current diagnostic and therapeutic practices and problems in patients with PID. The main speakers were prof. Alexandr Yarilin, chief of Cellular Immunology Department of the Institute of Immunology of Russia (Moscow), prof. Sergey Khaydukov of the Institute of Bioorganic Chemistry, Academy of Sciences (Moscow), and prof. Irina Kondratenko, chief of Clinical Immunology Department of Russian Children’s Clinical Hospital (Moscow). Prof. A. Yarilin presented an excellent overview about cellular interactions in the development of immune response. Next, prof. Khaydukov presented a report about methods of immunophenotyping of lymphocytes and



L–R:

Elena Deripapa,

Julia Rodina,

Alexandr Yarilin,

Svetlana

Vakhlarskaya,

Irina Kondratenko,

Olga Paschenko

using flow cytometry in clinical practice. Prof. I. Kondratenko with her colleagues from the Clinical Immunology Department (O. Pashchenko and doctor E. Deripapa) offered overviews of classification, clinical and laboratory presentations of severe combined immunodeficiencies combined T and B-cell immunodeficiencies, other well-defined immunodeficiency syndromes, phagocytic defects and algorithms for diagnosis and therapy of PID. Dr. A. Kapustina gave an update about hereditary angioedema. Most lectures were contented with case reports and gave rise to discussions with participants. The official language of the J Project Meeting in Moscow was Russian. Proceedings of the meeting will be published as a special issue of the Russian Journal of Pediatrics. The aim of our meeting was to train pediatricians and immunologists from out-patient departments of Moscow Region and post-graduate students about basic concepts in immunology and immunodeficiencies in practice.

Irina Kondratenko

CHERNIHIV, UKRAINE

April 5–6, 2012

Host: Liudmyla Chernyshova (*chernyshova@ukr.net*)

Venue: Hall of Regional administration

Main Topic: Primary immune deficiency in children – early diagnostics and treatment

PROGRAM

April 5

Achievements and problems of pediatric immunology in 2011

Chernyshova, L. (Ukraine)

Marker features of combined immune deficiencies in children

Kostyuchenko, L. (Ukraine)

Immunologic and genetic basis for atypical severe combined immune deficiency

Belevtsev, M. (Belarus)

First steps in diagnostics of PID in children in the Republic of Moldova

Cherempei, L. (Republic of Moldova)

Results of bone marrow stem cells transplantation in combined immune deficiencies in Ukrainian children

Porta, F. (Italy)

Vaccination of children with immune deficiency

Volokha, A. (Ukraine)

History of production of immunoglobulins

Skrynnik, M. (Ukraine)

Optimized model of regional center for clinical immunology in Urals federal region

Tuzankina, I. (Russia)

Care for children with primary immune deficiency in Latvia

Prokofjeva, T. (Latvia)

Session with patients and parents

April 6

Neutropenia in children

Samarin, D. (Ukraine)

Quality of life in children with primary immune deficiencies <i>Bondarenko, A. (Ukraine)</i>	Chromosomal instability syndrome in children <i>Savchak, I. (Ukraine)</i>
Defects of phagocytic system. Presentation of patient with deficiency of leucocyte adhesion <i>Lapyi, F. (Ukraine)</i>	New variant of mucocutaneous candidiasis <i>Romanishin, Y. (Ukraine)</i>
Immune deficiency of complement system <i>Boyko, Y. (Ukraine)</i>	Periodic fevers as a sign of primary immune deficiencies in children <i>Stepanovsky, Y. (Ukraine)</i>

SUMMARY AND CONCLUSION

The 8th Ukrainian J Project was held on April 5–6, 2012, in the city of Chernihiv. Chernihiv is a historic city located in the north of Ukraine. Throughout its history it was one of the main centers of political and economic, social and cultural life in Ukraine. In the southern part of the Kievan Rus' the city was the second by importance and wealth, now it is the administrative center of the Chernihiv Region. The estimated population of the city is about 300,000. Chernihiv region is the second largest territory in Ukraine after the Odessa region, and its population is about 11,097,000. The average population density is 34.8 people per km². The region is located in northern Ukraine, Polisky and forest-steppe zones of the Dnieper lowland. Forests cover 20% of the territory. The seminar was attended by about 200 doctors from the Chernihiv region and 20 immunologists from most regions of Ukraine as well as guests from Russia, and Belarus, Italy, and Latvia. At the beginning of the symposium Professor LI Chernyshova, the Head of the Ukrainian Association for Pediatric Immunology, highlighted the main achievements of Pediatric Immunology in Ukraine over the last decade and its prospects for development. Reports at the seminar were devoted to the diagnosis of major groups of PID, vaccination of patients with PID, as well as to the presentation of cases and characteristics of care for patients with PID in other countries (Russia, Belarus). The presentation of the cases took up most of the time in the workshop as the most effective method to be retained by doctors. In particular, a child with Wiskott-Aldrich syndrome coming from the Chernihiv region has recently returned home from Italy after successful stem cell transplantation. PID patient's parents were traditionally invited to participate in the seminar. Their reports described the clinical features of the disease, the path to the diagnosis of their children and the current problems they face during treatment. Their emotionally charged speeches traditionally made an impression on the audience and were very memorable. During patient's section the forming of a patient organization was discussed. Conducting School in an atmosphere of elation and lively discussions and their aim to attain international standards raises hope for more effective detection of primary immunodeficiencies in the Chernihiv region and effective cooperation in the future. Chernihiv is famous for its monuments of Kyivan Rus and the Principality of Chernihiv and Chernihiv Cossack Hetman Regiment. All through the most trying periods of its history, Chernihiv retained its ecclesiastical importance as the seat of a bishopric or an archbishopric. At the outskirts of the modern city lie two ancient

cave monasteries, formerly used as the bishops' residences. Participants of the seminar could view the most famous architectural monuments of the two most flourishing periods in the city's history – those of Kievan Rus' (11th and 12th centuries) and the Cossack Hetmanate (late 17th and early 18th centuries.) during their excursion on 6th of April.

Liudmyla Chernyshova

TALLINN, ESTONIA

April 19, 2012

Host: Krista Ress (*Krista.Ress@itk.ee*)

Venue: Radisson Blu Hotel Olümpia

Main Topic: New developments in the field of primary immunodeficiencies in children



PROGRAM

April 19

Newborn screening for severe primary immunodeficiencies

Borte, S. (Estonia)

Primary immunodeficiencies: Genetic predisposition to infectious diseases

Maródi, L. (Hungary)

Situation of PID in Estonia

Ress, K. (Estonia)

C1 esterase inhibitor deficiency

Kuuse, R. (Estonia)

SUMMARY AND CONCLUSION

The J Project meeting was held in Tallinn, Estonia on 19th of April, 2012, in order to celebrate the Day of Immunology and World PI Week. The meeting was organized by the Estonian Society for Immunology and Allergology jointly with the Tallinn Pediatric Association to raise the recognition and diagnosis of primary immunodeficiencies in Estonia. More than 130 pediatricians, allergologists-immunologists and scientists from Estonia attended the Meeting. Current situation of PID diagnostic and therapeutic practices were discussed. We had two excellent international speakers Dr. Stephan Borte and Prof László Maródi. Stephan Borte spoke about the possibilities and his experience in newborn screening for severe primary immunodeficiencies. Prof

Maródi gave an overview about the history of the J Project and previous meetings and afterwards an interesting lecture about genetics in PID together with interesting cases. Dr. Krista Ress from the East-Tallinn Central Hospital JMF Center gave an overview about the current situation of diagnosed PID cases and about the diagnostic possibilities in Estonia. Dr. Reet Kuuse from Tartu University Clinics presented a case story about C1 esterase inhibitor deficiency. As the main aim of the meeting was to raise awareness of diagnostic possibilities in PID, we could consider the meeting as a success.

Krista Ress

TEHRAN, IRAN

April 22, 2012

Host: Nima Rezaei (rezaei_nima@yahoo.com)

Venue: Qarib Conference Room, Children's Medical Center Hospital

Main Topic: Awareness of World PI Week for Basic and Clinical Immunologists

SUMMARY AND CONCLUSION

The 67th J Meeting was organized in Tehran, Iran during the World PI Week (22nd–29th April 2012). The Research Center for Immunodeficiencies (RCID) and the Children's Medical Center (the Pediatrics Center of Excellence in Iran) affiliated to Tehran University of Medical Sciences, organized an immunodeficiency seminar (Qarib Conference Room, Children's Medical Center Hospital, Sun 22nd April 2012, 8:00–16:00). Pediatricians as well as basic and clinical scientists attended the meeting to explore case discussions, review immunodeficiency research and engage in panel discussions. The meeting also brought together junior scientists and the media were invited for interviews. The RCID also invited Basic and Clinical Immunologists to attend the Immunodeficiency session during the 11th International Congress of Immunology and Allergy of Iran (April 26th–29th, 2012). The session was titled "Awareness of World PI Week for Basic and Clinical Immunologists" (Hall 5, Milad Tower, Fri 27th April 2012: 11:00–13:00), and comprised keynote lectures; short talks on original studies; case discussions and an immunodeficiency panel discussion.



Nima Rezaei



BRATISLAVA, SLOVAKIA

April 27, 2012

Host: Peter Ciznar (*ciznar@dfnsp.sk*)

Venue: Children's Faculty Hospital

Main Topic: 2nd J Project Symposium on primary immunodeficiencies: early diagnosis and treatment



PROGRAM

April 27

Immunogenetic basis of autoinflammatory diseases

Buc, M. (Slovakia)

Periodic fever: clinical approach

Toplak, N. (Slovenia)

CINCA syndrome

Vargová, V. (Slovakia)

Monogenic autoinflammatory syndromes

Debeljak, M. (Slovenia)

PFAPA syndrome

Ciznar, P., Dalos T. (Slovakia)

Genetic diagnostics of PID

Freiberger, T. (Czech Republic)

SUMMARY AND CONCLUSION

The second J Project Symposium was held at the Lecture room of the Children's University Hospital in Bratislava, during the World Immunodeficiency Week and the World Immunology Day, a global campaign supported by the World Health Organization, the European Society for Immunodeficiency, the American Society for Primary Immunodeficiency and patient organizations promoting activities to improve care for PID patients. Concurrently the symposium was under the auspices of the Slovak Society of Clinical Immunology and Allergology and Slovak Immunology Society and co-organized by the Jeffrey Modell Foundation. J Project symposium 2012 had been attended by almost 100 participants, 70 registered as members of the Slovak Medical Chamber. Professor Buc, professor of immunology at the Institute of Immunology Faculty of Medicine in Bratislava, our colleagues from Ljubljana, Slovenia, Dr. Natasa Toplak and Marusa Debeljak and also our colleague from Brno, the Czech Republic, Dr. Tomas Freiburger. The symposium was divided into four thematic sections: autoinflammatory syndromes, genetic diagnosis in primary immunodeficiencies and two sections of case presentations. Lectures were focused mainly on primary care physicians, but allergologists and regional immunologists from all over Slovakia had registered as well. The relatively new topic of autoinflammation was probably the most appreciated. Dr. Toplak presented a broad clinical approach to patients with monogenic autoinflammatory syndromes, supported by many personal experiences. Dr. Debeljak focused on laboratory diagnosis and genetic testing in Slovenia and surrounding countries. The topic of PID genetics presented by renowned geneticists from Slovakia and the Czech Republic was probably the first occasion to present this specific topic in a comprehensive way. According to the evaluation reports given by the participants, the Symposium was regarded as highly professional, exceeding the expectation of many of them and beneficial for general and specialized physicians as well. Hopefully we had started a new tradition in Slovakia of annual PID meetings as a platform to keep the PID topic growing.

Peter Ciznar

DIYARBAKIR, TURKEY

May 12, 2012

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

Venue: The Green Park Hotel, Diyarbakir

Main Topic: Diagnosis and management of primary immunodeficiencies

PROGRAM

May 12

Awareness on primary immunodeficiency diseases (PIDs)

Reisli, I. (Turkey)





Ismail Reisli

Classification of PIDs and screening tests

Tuncel, T. (Turkey)

Sign and symptoms of PIDs in childhood

Reisli, I. (Turkey)

PIDs in adulthood

Caliskaner, Z. (Turkey)

Management of PIDs

Reisli, I. (Turkey)

SUMMARY AND CONCLUSION

Because of the high ratio of consanguinity, I believe that primary immunodeficiency (PID) is an important public health problem in Turkey. We had planned to organise educational meetings in Anatolia, especially Eastern Anatolia where there are no immunologist specialists, to increase the awareness on primary immunodeficiency diseases among physicians. This J Project Meeting in Diyarbakir was the first one in Eastern Anatolia and the third J Project Meeting in Turkey. The Diyarbakir J Project Meeting was held on May 12, 2012. The meeting was organized by Dr. Tuba Tuncel, a talented and ambitions colleague, from the Department of Pediatric Immunology and Allergy, Medical School of Dicle University. The meeting was primarily focused on the awareness, clinical signs and treatment of PID for medical students and physicians (pediatricians, family physicians), and also on discussing the importance of



early diagnoses. More than 50 participants attended the meeting. The meeting was started with an opening lecture by Prof. Dr. Ismail Reisli focusing on the awareness of primary immunodeficiency. After this, four lectures were given at the meeting which were all based on diagnostic problems, clinical manifestations, screening and treatment of PID. The first part of the meeting was started with a lecture about the classification and screening tests of PID by Assist. Prof. Dr. Tuba Tuncel of Dicle University (Diyarbakir) and continued with the warning signs in children with PID by Prof. Dr. İsmail Reisli of Necmettin Erbakan University (Konya). The second part of the meeting was dedicated to the warning signs of PID in adults by Prof. Dr. Zafer Caliskaner of Necmettin Erbakan University (Konya) and the management of PID by Prof. Dr. İsmail Reisli. I would like to thank all speakers and participants for their contributions, especially our sponsor (Gen Ilac) for their general help which made it possible to organize this event.

Ismail Reisli

PRAGUE, CZECH REPUBLIC

May 14–15, 2012

Host: Anna Sediva (*Anna.Sediva@fnmotol.cz*)

Venue: Department of Immunology, 2nd Medical School, Charles University, University Hospital Motol, Prague

Main Topic: 11th ESID Prague Spring Meeting and 70th J Project Meeting

PROGRAM

May 14

Strategies for immunoglobulin treatment

Espanol, T. (Spain)

Non-BTK agammaglobulinemia

Veghova, L., Ciznar, P. (Slovakia)

CVID-like disorder, EBV-Associated lymphoproliferative disease and life-threatening lymphoma in patients lacking functional CD27

Salzer, E. (Austria)

Thymoma associated hypoagammaglobulinemia and oral lichen planus

Kralickova, P., Malá, E., Rozsival, P., Parizková, E. (Czech Republic)

B lymphocyte compartment in diGeorge syndrome

Klocperk, A. (Czech Republic)

Good's syndrome: a combined immunodeficiency? First case report in Algeria

Messaoudani, N. (Algeria)

B-cell subsets phenotype in autoimmunity with immunodeficiency: analysis of a large cohort of patients with APECED syndrome

Magnani, A. (Italy)

TTNFRSF13B mutations in Czech CVID and IgAD patients.

Freiberger, T., Ravcukova, B., Grodecka, L., Litzman, J. (Czech Republic)

High throughput genomics for discovery of novel primary immunodeficiencies

Boztug, K. (Austria)

Heterozygous activating mutation in CEBPE gene in a patient suffering from specific granule deficiency (SGD)

Mejstrikova, E. (Czech Republic), Prengemann, K. N. (Austria)

A novel mutation in the complement factor 3 gene

Santos-Valente, E. (Austria)

- Clinical symptoms of HAE in a two-year-old child
Gutova, V. (Czech Republic)
- Autoinflammatory diseases
Llobet, P. (Spain)
- Mitochondrial changes in a patient with Schnitzler syndrome
Sediva, A. (Czech Republic)
- May 15**
- Combined immunodeficiency beyond infancy – a challenge in diagnosis and management
Speckmann C. (Germany)
- Combined immune deficiency with high gamma-delta cells
Litzman J. (Czech Republic)
- A case of CD4 lymphopenia: from father to child
Monteferrario E. (Italy)
- Two cases of severe combined immunodeficiency (SCID) – met more often than expected
Paukert J., Sipova V. (Czech Republic)
- Targeted screening for severe combined immune deficiency (SCID) among high risk neonates using T-cell receptor excision circles (TRECS)
Youssif R. (Egypt)
- Genetic diagnosis of primary immunodeficiency in Iran
Houshmand M. (Iran)
- Transplantation for primary immunodeficiency
Gennery A. (United Kingdom)
- Hematopoietic stem cell transplantation in Omenn syndrome
Formankova R. (Czech Republic)
- Recurrent infections: how to surf
Moschese V. (Italy)
- DOCK8 deficiency as a rare variant of hyper IgE syndrome (clinical case)
Romanyshyn Y. (Ukraine)
- Family case of Comel-Netherton syndrome
Kostyuchenko L. (Ukraine)
- Follow-up of 9 years old girl with Netherton syndrome
Zachova R., Capkova S. (Czech Republic)
- Autoimmune complication in ataxia teleangiectasia
Sembroba J. (Slovakia)
- Hemolytic Anemia, Immunodeficiency with neutropenia in a 15-month-old Egyptian boy
Nodal R. (Egypt)
- Genetic and immunological features of MHC II deficiency in ten Algerian patients
Messaoudani N. (Algeria)

SUMMARY AND CONCLUSION

This traditional ESID and J Project meeting was attended by 48 participants from 12 countries, the majority of them from the Czech Republic, further from Austria, Belarus, Egypt, Germany, Italy, Poland, Slovakia, Spain, Ukraine, United Kingdom, and Iran. CVID was covered by Teresa Espanol from Spain. SCID and screening programs were introduced by Carsten Speckman from Germany. Kaan Boztug from Austria gave a presentation of modern genetics and its application to the field of PIDs. Andy Gennery from the UK chaired the section on therapy, and finally Viviana Moschese from Italy supervised the clinical and case reports section. Students of the Academy of Fine Arts in Prague were again involved. This year they prepared a particularly special contribution by painting portraits of invited speakers, which were



L-R: Teresa Espanol, Anna Sediva, Andy Gennery, Viviana Moschese, Carsten Speckmann

given thank for their very active and voluntary participation. The meeting was organized as a part of the Day of Immunology program, declared by EFIS on 29th April, 2012, and of the PI week, 2012. The meeting is also an event of J Project meetings, promoting awareness about PIDs in Central and Eastern European Countries. ESID Prague Spring Meeting was supported by the Charles University, 2nd Medical School, Prague and by University Hospital Motol, Prague. Substantial contributions came from the traditional sponsor Olympus and by Baxter, Biomedica ČS, Exbio, Grifols and Synlab in alphabetical order and by Czech Immunology Society. We thank the participants for their contributions and hope to see them again next year in Prague.

Anna Sediva

KONYA, TURKEY

May 26–27, 2012

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

Venue: Department of Pediatric Immunology of Necmettin Erbakan University Meram Medical Faculty at Dedeman Convention Center

Main Topic: Diagnostics, treatment and complications of PID

PROGRAM

May 26 Recurrent infections due to non-immunodeficiencies
Yildiran, A. (Turkey)

Infections in classical immunodeficiencies
Aksu, G. (Turkey)
Infections in non-classical immunodeficiencies
Keles, S. (Turkey)

Non infectious signs of Immunodeficiencies <i>Artac, H. (Turkey)</i>	Awareness of immunodeficiency in Turkey <i>İkinciogullari, A. (Turkey)</i>
Autoimmunity and malignancy <i>Ardeniz, Ö. (Turkey)</i>	May 27
Allergic diseases and immune dysregulation in immunodeficiency <i>Gulec, M. (Turkey)</i>	The evolution of immunology as a discipline in Turkey <i>Sanal, Ö. (Turkey)</i>
Antibody deficiencies <i>Camcioglu, Y. (Turkey)</i>	Diagnosis of immunodeficiency in Turkey <i>Yegin, O. (Turkey)</i>
Cellular immune defects <i>Kilic, S. (Turkey)</i>	Genetic analysis of immunodeficiencies in Turkey <i>Güner, S. (Turkey)</i>
Phagocytic cell defects <i>Metin, A. (Turkey)</i>	Immunological diagnosis of PIDs <i>Yukse, M. (Turkey)</i>
Complement defects <i>Yilmaz, M. (Turkey)</i>	Evaluation of patients before stem cell transplantation <i>Dogu, E. F. (Turkey)</i>
Signs and symptoms of PIDs <i>Musabak, U. (Turkey)</i>	Stem cell transplantation <i>Tezcan, İ. (Turkey)</i>
Treatment and follow-up of PID patients <i>Çalışkaner, Z. (Turkey)</i>	Turkish Society of Immunology: an introduction <i>Deniz, G. (Turkey)</i>
Effects and indications of Ig treatment <i>Harmanci, K. (Turkey)</i>	Turkish National Society of Allergy and Clinical Immunology <i>Tuncer, A. (Turkey)</i>
Cautions in practice <i>Aytekin, C. (Turkey)</i>	Patients' society of immunodeficiency in Turkey <i>Kay, S. (Turkey)</i>
Current vaccines in Turkey <i>Kutlu, R. (Turkey)</i>	
Vaccination in primary immunodeficiency <i>Orhan, F. (Turkey)</i>	

SUMMARY AND CONCLUSION

The second J Project Meeting in Konya, also the fourth in Turkey, was held on 26–27 May, 2012. The meeting was organized by the Department of Pediatric Immunology of Necmettin Erbakan University Meram Medical Faculty at Dedeman Convention Center. The main objectives of the meeting were to improve awareness on primary immunodeficiencies (PID) among the medical students, physicians, pediatricians and other specialists, to discuss PID diagnostic problems, clinical symptoms, treatments, and to clarify the importance of early diagnosis of PID. The meeting was attended by more than 200 participants. Among the guests, there were immunologists from different centers in Turkey, and also the presidents of the Turkish Society of Immunology, the Turkish National Society of Allergy and Clinical Immunology, the Immunodeficiency Society, and the (Patients Society). Twenty six lectures were given in eleven sessions during the two days. The panels were based on diagnostic, treatment and complications of PID. I think that the most important lectures were given by the pres-



idents of the societies to make it possible to discuss the problems of immunologists and the patients in Turkey. To round off the first day, the shuttle buses transferred the participants to a nice restaurant which was situated near Meram to have a traditional Konya dinner. I would like to thank all speakers and participants for their contributions, especially the presidents of the societies, our sponsor (Eczacıbaşı-Baxter) for the generous help which made it possible to organize this meeting.

Ismail Reisli

WARSAW, POLAND

June 1–2, 2012

Host: Ewa Bernatowska (*bernatowskaw@yahoo.com*)

Venue: Holiday Inn Hotel

Main Topic: Conference of the Polish Working Group on Primary Immunodeficiencies

PROGRAM

June 1

Access to National Health Fund services and activities to improve care of patients with primary immunodeficiencies. Training in the Specialty in the field of clinical immunology – the need for change

Bernatowska, E. (Poland)

Objectives and tasks of the national consultant in the field of clinical immunology

Siedlar, M. (Poland)

Summary of results of stem cell transplantation in children with severe

combined immune defects from the national centers and the present opportunities for biological therapy in children with primary deficiencies

Wolska – Kusnierz, B. (Poland)

Treatment with gamma globulins in children – data from the national Centers for Diagnosis and Treatment of Primary Immunodeficiencies

Pac, M. (Poland)

Replacement therapy with subcutaneous gamma globulins for adults. – A single center experience.

Rolinski, J. (Poland)

Present and future of diagnosis and treatment of primary immunodeficiency disorders in Poland – from birth to elderly age.

– Contribution by all participants

June 2

Short talks about: access to the services of the National Health Fund (diagnostic, therapeutic procedures, including treatment with gamma globulins, prevention with antibiotics and antifungal drugs, and biological treatment), improving the care of children and adults with primary immunodeficiencies.

Discussion with parents, patients, doctors

The creation of the Earth – presentation of 15-year-old *Kuba Nowicki*, a patient with Wiskott – Aldrich syndrome after BMT

Presentation of the film „Batman – the city of terror” – presentation of 12-year-old *Dominik Skiba*, a patient with SCID after BMT

Care for children with recurrent fever syndromes

Wolska –Kusnierz, B. (Poland)

My professional future

Dudkiewicz, K. (Poland)

Foundation for children and adults with chronic granulomatous disease

Górniak, P. (Poland)

My adult child

Niedźwiedzka, A. (Poland)



L–R: Bożena Kusmirek (nurse) with patient’s mom



CGD Patient group

SUMMARY AND CONCLUSION

The conference of the Polish Working Group on Primary Immunodeficiencies was organized on June 1st, 2012 in the framework of J Project and JMF Grant Foundation in cooperation with patients with immunodeficiency and their parents. The venue for the conference was located in a very convenient place, in a green area of Warsaw. Forty-five clinical immunologists, pediatricians and internists discussed the important issue of how to improve care of patients with primary immunodeficiencies. Since 1993 the replacement therapy with both intravenous and subcutaneous immunoglobulins for children with hypogammaglobulinemia up to 25 years of age has been fully guaranteed by the National Health Fund. The National Therapeutic Program is not yet established for adult patients, therefore access to National Health Fund services is limited. Replacement therapy for adults has been provided by six main centers. The

regional hospitals don't do it because of the high costs of therapy. So, adults from peripheral polish regions still had difficulties in having access to proper diagnosis and therapy. Conference of the parents and children with primary immunodeficiencies was organized on June 2nd, 2012 by the Polish Working Group on Primary Immunodeficiencies. The number of parents and patients with primary immunodeficiency amounted to 76 participants. The next conference will be organized on September, 2013.

Ewa Bernatowska

SIBIU, ROMANIA

June 2, 2012

Host: Sorin Iurian (*iurian_sorsab@hotmail.com*)

Venue: Continental Forum Hotel

Main Topic: Primary immunodeficiencies as clinical and molecular genetic diagnostic challenges

PROGRAM

June 2

Primary immunodeficiencies associated with juvenile idiopathic arthritis.

Iagaru, N., Enculescu, A., Moraru, C., Covaci, S. (Bucharest)

Immunosuppressive therapy in primary immunodeficiencies.

Iagaru, N., Moraru, C., Covaci, S. (Bucharest)

Diagnostic difficulties in a case with severe neutropenia.

Sorin, I., Bataneant, M., Gradinariu, G., Soroiu, C. (Timisoara)

A severe neutropenia case report

Sorin, I., Motoc Stanca, R., Dumitra, R. (Sibiu)

Patients' profile and quality of life according to National Programme for PIDs therapy in adults.

Cristea, V., Miron, N., Manea, I. (Cluj-Napoca)

Interleukin pattern for PFAPA patients.

Sorin, I. (Sibiu)

Peculiarities of 2 cases with primary immunodeficiency

Gherghina, I., Iagaru, N., Cochino, A. (Bucharest)

A family with WHIM syndrome

Bataneant, M. (Timisoara), Herghelegiu, I. (Timisoara), Alexandra, L. (Timisoara), Matis, B. (Timisoara), Maródi, L. (Debrecen), Serban, M. (Timisoara)

Cases with ataxia-telenagiectasia syndrome.

Nuta, C., Moraru, C., Plaiasu, V., Iagaru, N., (Bucharest)

Phagocytosis anomalies in neonates.

Gradinariu, G., Ognean, L. (Sibiu)

Primary immunodeficiency in Sibiu County: future perspectives.

Sorin, I. (Sibiu)

SUMMARY AND CONCLUSION

The 73th J Project Meeting was held in Sibiu on 2nd of June, 2012. This conference represented the 8th J Project Meeting organized in Romania and the 2nd Meeting held in Sibiu. We hope that Sibiu will become a constant host for J Project Meetings during the next decade. More than 30 physicians (specialists and residents in pediatrics/immunology and general practitioners) from other medical universities (Iasi, Timisoara, Cluj-Napoca, and Bucharest) attended this symposium and a few of them have presented their experience regarding PID diagnosis. We also encouraged the participation of mothers belonging to an association named “United Hands”, asking them their support. Also, there were unsolved cases with primary immunodeficiency presented, offering an opportunity to receive information from colleagues with experience in PIDs to establish a diagnosis algorithm. During a previous meeting held in Sibiu in June 2011, we mentioned our intention to initiate a diagnosis and treatment center for PIDs in Sibiu, using genetic diagnostic methods in the context of support from Professor László Maródi and his team colleagues. In order to accomplish this purpose, we initiated an ambitious plan for a DNA sequencer acquisition that represents an important step for PID diagnosis in pediatric population not only for Sibiu County, but also in other neighboring regions. We launched articles in the local media to let people know about our project and ways to collect funds. The first part of this project was fulfilled on 16th of June due to an initiative from Sibiu Community Foundation together with “United Hands”, collecting funds for our project. We will continue to sustain courses about basics in immunology and primary immunodeficiencies (for general practitioners, residents in pediatrics, medical students) for improving knowledge about PIDs.

Sorin Iurian



*Participants
of the Meeting*

Host: Elissaveta Naumova (*naumovaej@gmail.com*)

Venue: Tzigov Chark

Main Topic: National Conference and J Project Meeting on Primary Immuno-deficiency Diseases (PID) and Autoimmunity

PROGRAM

June 8

PID as a rare disease-consensus and resolutions from the Workshop, held in June 2010, Plovdiv

Murdjeva, M. (Bulgaria)

Rare diseases in Bulgaria: current status and perspectives.

Stefanov, R. (Bulgaria)

Current status of the Bulgarian PID patients.

Stefanov, R., Naumova, E. (Bulgaria)

PID with predominantly antibody deficiency.

Naumova, E., Mihaylova, A. (Bulgaria)

Combined immunodeficiencies.

Popova, D. (Bulgaria)

Phagocytic cell disorders.

Martinova, F. (Bulgaria)

Complement deficiencies.

Baleva, M., Murdjeva, M. (Bulgaria)

Monitoring and management of children with PID associated with susceptibility to malignancies.

Spasova, M. (Bulgaria)

Human genetic defects in the innate immune system

Picard, C., (France)

Clinical and immunological manifestations of CVID

Warnatz, K., (Germany)

Novel genetic defects causing chronic mucocutaneous candidiasis

Maródi, L. (Hungary)

Antibiotic therapy as a prophylaxis in PID patients

Kantardjiev, T. (Bulgaria)

SCIG as a gift for patients with antibody deficiency

Maródi, L. (Hungary)

IgA Deficiency in patient with Addison's disease.

Naumova, E., Baleva, M., Atanasova, I., Mihailova, S., Yankova, P., Altankova, I., Nikolov, K. (Bulgaria)

Case report of IgA deficiency-questions and challenges

Halacheva, K.

Case report on CVID

SUMMARY AND CONCLUSION

The 2012 Annual National Conference on “Primary immune deficiencies and autoimmunity” organized by the Bulgarian Association for Clinical Immunology, Medical University-Plovdiv and the J Project was held in Tzigov Chark on 8–9 June 2012. The key topics of the program were focused on the current trends and consensus in the diagnosis and treatment of PID as well as on the possibilities of standardization of algorithms for diagnostics of PID in Bulgaria. Renowned experts on PID from Bulgaria, France, Germany, Hungary etc. were invited to give lectures on issues related to current knowledge of PID. The Plenary Session was followed by a session on:

“PID and Autoimmunity” – at which case reports were mostly presented. Interesting clinical cases were presented and discussed by the participants during this session. The meeting was attended by more than 60 participants including PID patients from Bulgaria who participated actively in the discussions on various aspects of PID. Leading companies, i. e., suppliers of the laboratory equipment, tests, and reagents applied in the field of immune diagnostics as well as those producing newly manufactured drugs for patients with PID presented during the meeting. There was also a particular focus on subcutaneous infusion of gamma globulin that has already been registered in Bulgaria. The conference was held in a friendly and relaxing atmosphere with lively discussions during the sessions. Many new friendships were made and old ones were renewed during the meeting leading to useful contacts for future collaboration. Since 2005, when Bulgaria joined the J Project, this conference was the third one held within the Project in our country. Participation in the J Project has contributed to both a better management and treatment of the PID patients and the raising of the public awareness of PID diseases in Bulgaria.

Elissaveta Naumova



Meeting delegates



Social event

Host: Panteley Popandopulo (*panteley.popandopulo@octapharma.com*)
Nurzhan Otarbayev (*otarbaev@rambler.ru*)

Venue: National Research Center

Main Topic: Important issues on maternal and child health and J Project Meeting

SUMMARY AND CONCLUSION

The 75th J Project Meeting was held in Astana, June 14–15, 2012 within the Republican Scientific-Practical Conference with International Participation. The main topic was “Important issues on maternal and child health”. This event was held in the National Research Center of motherhood and childhood.

There were 2 PID focused reports:

PROGRAM

June 14

Diagnostics and treatment of primary immunodeficiency disorders.

Maródi, L. (Hungary)

June 15

Intravenous immunoglobulin use in practice of pediatricians.

Panteley, P. (Kazakhstan)

Dr. Maródi met with prof. Nurzhan Otarbayev, Chief Medical Officer of the Republican Center of Maternity and Childhood, prof. Ernas Tuleutayev, Head of the Pediatric Division of the Republican Center of Maternity and Childhood and they discussed the organization of the State program for PID treatment in Kazakhstan.

Then doctor Maródi met with opinion-leaders – team for organization of work associates with PID: Prof. Helen Kovzel Chief Immunologist of Kazakhstan, prof. R. I. Rozenson immunologist and prof. M. A. Morenko immunologist.



Meeting with Azhar Tulegalieva in the Ministry of Health. L–R: Panteley Popandopulo, László Maródi, Azhar Tulegalieva, Nurzhan Otarbayev

Afterwards, they visited the Laboratory of the National Diagnostic Center and the Laboratory of the Center of Maternity and childhood. Also, they inspected equipment in the Centers. They concluded that equipment in the Centers was sufficient for conducting of basic PID diagnostic tests (with the exception of the gene sequencer). Then they met with Azhar Tulegalieva (Director of the Treatment and Preventive Medicine Department) in the Ministry of Health and during the meeting they agreed on the promotion and support of J Project in Kazakhstan.

Panteley Popandopulo

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

Venue: Tyumen Technopark (West-Siberian Innovative Center)

Main Topic: 10th Anniversary Russian Conference of Ural's Immunologists and the 76th J Project meeting

PROGRAM

July 2

PRIMARY IMMUNODEFICIENCIES

Practical approaches to the diagnosis of primary immunodeficiencies

Prodeus, A. (Russia)

The organizational model of the regional center for clinical immunology, optimizing observation of patients with PID

Tuzankina, I. (Russia)

Rare clinical manifestations of PID: and observational study in the Chelyabinsk region.

Pishchalnikov, A. (Russia)

Primary immunodeficiencies with lethal outcome

Vlasova, E. (Russia)

Immunological methods for the laboratory diagnosis of PID

Pashnina, I. (Russia)

The combination of maternal polymorphisms of TNFA (rs1800629) and GSTT1 genes with congenital malformations of a fetus and a newborn

Gordeeva, L., Glushkova, O., Shatalina, I., Popova, O., Voronina, E., Ermolenko, N., Gareeva, Yu., Simonova, T., Sutulina, I., Philipenko, M. (Russia)

The Urals region is located in the middle of Russia, at the border between Europe and Asia. Urals territory consists of Sverdlovsk region, Chelyabinsk, Kurgan, Tyumen, Yamalo-Nenetsk, Khanty-Mansiysk, Komi, Perm, Bashkiria and Arkhangelsk regions. The 76th J Project Meeting was held in Tyumen in July 2012. Two hundred people from 21 cities including Moscow, St. Petersburg, Chelyabinsk, Ufa, Perm, Yekaterinburg, Novosibirsk, Izhevsk and Tyumen attended the conference. The

participants of the Meeting included heads of departments of medical academies, doctors and heads of departments of hospitals, post-graduate students of various institutions, as well as interns.

Irina Tuzankina



Irina Tuzankina (middle) with colleagues

Host: Tadej Avcin (*tadej.avcin@siol.net*)

Venue: Medical faculty, University of Ljubljana

Main Topic: Recognition and Treatment of Primary Immunodeficiency

PROGRAM

September 14

Epidemiology and classification of PID

Avčin, T. (Slovenia)

Early recognition of patients with PID

Markelj, G. (Slovenia)

Infections, antimicrobial treatment and prophylaxis in PID patients

Pokorn, M. (Slovenia)

Application of flow cytometry in the diagnosis of PID

Ihan, A. (Slovenia)

Genetic testing in the diagnosis of PID

Debeljak, M. (Slovenia)

Treatment and prognosis of PID

Toplak, N. (Slovenia)

Bone marrow transplantation in PID

Jazbec, J. (Slovenia)

Case presentation

Jeverica, A. K. (Slovenia)

Case presentation

Markelj, G. (Slovenia)

Autoimmunity in primary immunodeficiency diseases

Abinun, M. (United Kingdom)

September 15 (Primary Immunodeficiency Awareness Day)

Venue: University Children's Hospital, UMC Ljubljana

Introduction

Avčin, T. (Slovenia)

Function of immune system

Blazina, Š. (Slovenia)

Prevalence and classification of PID

Avčin, T. (Slovenia)

Clinical presentation of PID

Markelj, G. (Slovenia)

Management and outcome of PID

Toplak, N. (Slovenia)

Diet and nutrition for PID patients

Čampa, A. (Slovenia)



Tadej Avcin is giving his talk

SUMMARY AND CONCLUSION

On the first day we organized a meeting for physicians of various specialties including pediatricians, internists, infectologists and general practitioners with interest in patients with PID. In total, 130 physicians participated at the meeting. On the second day we organized a PID awareness day for patients with PID and their families. The PID awareness day was attended by 300 participants and included an entertainment program for children and general lectures for parents on the immune system, the recognition and treatment of PID and on nutrition of patients with immune deficiencies.

TEHRAN, IRAN

October 13–14, 2012

Host: Nima Rezaei (*rezaei_nima@yahoo.com*)

Venue: Children's Medical Center Tehran University of Medical Sciences

Main Topic: 5th Meeting on Clinical Immunology and Immunodeficiencies

PROGRAM

October 13

Immunological Phenotypes of Common Variable Immunodeficiency

Warnatz, K. (Germany)

Principles of Hematopoietic Stem Cell Transplantation in Immunodeficiencies

Hamidieh, A. A. (Iran)

Approach to a Child Susceptible to Infection

Aghamohammadi, A. (Iran)

Approach to a Child with Congenital Neutropenia

Rezaei, N. (Iran)

Approach to a Child with Food Allergy

Troncone, R. (Italy)

Approach to a Child with Asthma

Moin, M. (Iran)

Approach to a Child with Atopic Dermatitis

Gharagozlou, M. (Iran)

Approach to a Child with Allergic Rhinitis

Movahedi, M. (Iran)

October 14

Clinical Phenotypes of CVID: The European Experience

Warnatz, K. (Germany)

Primary Immunodeficiencies in Asia: Today and Future

Aghamohammadi, A. (Tehran)

Recent Advances on Diagnosis of Primary Immunodeficiencies in Iran

Rezaei, N. (Iran)

Primary Immunodeficiencies in Azerbaijan and North-Western Iran

Shabestari, M. S. (Iran)

Mendelian Susceptibility to Mycobacterial Disorders in Iran

Mahdaviani, S. A. (Tehran)

Chediak-Higashi Syndrome: A Report from the North of Iran

Ghaffari, J. (India)

Molecular Basis of Autosomal Recessive Chronic Granulomatous Disease in Iran

Teimourian, S. (Tehran)

Immunomodulatory Effects of Probiotics in the Management of Lung Diseases

Mortaz, E. (The Netherlands)

New Advances in Treatment of Allergic Rhinitis

Alyasin, S. (Iran)

Immunologic Markers in Patients with β -Thalassemia

Ahmadiafshar, A. (Iran)

A Study of Atopy Frequency in Patients with Anticonvulsant Drug Hypersensitivity and Control Group

Chavoshzadeh, Z. (Tehran)

Serum Level of Zinc in Asthmatic Patients; a Case-Control Study

Khanbabaee, G. (Tehran)

TNF-alpha Single Nucleotide Polymorphisms in Atopic Dermatitis

Behniafard, N. (Tehran)

Gene Polymorphisms of Tumor Necrosis Factor and Interleukin-1 Gene Complex in Allergic Rhinitis

Nasiri, R. (Tehran)

Decreased Circulating $CD4^+CD25^+$ Foxp3⁺ T Cells in Chronic Autoimmune and Chronic Idiopathic Urticaria

Babaie, D. (Tehran)

Multiple Cancers in a Patient with Common Variable Immunodeficiency

Esmaeilzadeh, H. (Tehran)

Diffuse Candidia Esophagitis in a Patient with Agammaglobulinemia

Momen, T. (Iran)

VCP (Vocal Cord Paralysis) Mimics Persistent Asthma

Bahrami, A. (Tehran)

SUMMARY AND CONCLUSION

The 5th Meeting on Clinical Immunology and Immunodeficiencies, which is also considered as the 78th J Project Meeting, was organized on October 13–14, 2012. 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 to present an update in this field. In October 2009, alongside with the 21st International Congress of Pediatrics, a joint meeting on Immunodeficiency Diseases was established. That two-day meeting was supported by the Jeffrey Modell Foundation (JMF). The great success of these conferences brought up 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 as the 46th J Project Meeting, was organized by the Research Group for Immunodeficiencies in collaboration with the Department of Pediatrics, Children's Medical Center Hospital, Tehran University of Medical Sciences. In 2011, as an established Re-



L–R: Riccardo Troncone, Nima Rezaei, Klaus Warnatz

search Center for Immunodeficiencies, the 4th Meeting on Clinical Immunology and Immunodeficiencies was organized, while a number of experts from the NIH and the University of Washington, US attended and presented talks at that meeting. This year, the 5th Meeting on Clinical Immunology and Immunodeficiencies, also considered as the 78th J Project Meeting, was organized along with the 24th International Congress of Pediatrics to focus on the linkages of fundamental sciences and patient-oriented research under the main theme of clinical immunology and immunodeficiency diseases. We are very pleased to host a total of more than 1,000 delegates at this meeting this year. Main lectures on “Primary Immunodeficiencies: General aspects” was the intro session in the main hall with some talks regarding approach to immunodeficiency, neutropenia, CVID and hematopoietic stem cell transplantation. Regional reports of immunodeficiencies and selected oral presentations on clinical immunology “From Bench to Bedside” were two different sessions in hall 2, which were organized on the 2nd day of the meeting. There were other two different sessions for poster presentations. The Expert Iranian PID session and the Case discussion session were also interactive parts of the meeting.

Nima Rezaei

TIMISOARA, ROMANIA

October 25–26, 2012

Host: Serban Margit (*mserban@spitalcopiitm.ro*)

Mihaela Bataneant (*mihabataneant@yahoo.com*)

Venue: Victor Babes University of Medicine and Pharmacy, Timisoara

Main Topic: Developmental and primary immunodeficiency disorders

PROGRAM

October 25

TH-17-mediated immunity in healthy human newborns

Bársony, A., Soltész, B., Taskó, Sz., Maródi, L. (Hungary)

Primary immunodeficiencies as diagnostic challenges

Serban, M., Bataneant, M., Romanian PID Study Group (Romania)

X-linked agammaglobulinemia in a boy with 47, xxy karyotype

Cochino, A. V., Freiburger, T., Plaia-su, V., Ochiana, D., Ravcukova, B., Gherghina, I. (Romania)

A fever syndrome of rare etiology

Negrutiu, L., Bataneant, M., Gaspar, C. (Romania)

A novel large deletion and single nucleotide insertion in the Wiskott-Aldrich syndrome protein gene

Soltész, B., Bársony, A., Gulácsy, V., Petrescu, C., M. Bataneant, M. Serban, Maródi, L. (Hungary, Romania)

Partial diGeorge syndrome: case presentation

Ellenes Z., Popa, C., Bataneant, M., Serban, M., Bendea, M. (Romania)

The role of hematopoietic stem cell transplantation in chronic granulomatous disease: The Timisoara experience

Jinca, C., Arghirescu, S., Bataneant, M., Oprisoni, A., Isac, A., Ciocarlie, O., Balan, A., Baica, M., Ordodi, V., Gai, E., Serban, M. (Romania)

Neutropenia case reports

Sorin, I., Maródi, L., Bataneant, M., Soroiu, C., Bacila, N. (Romania, Debrecen)

Recent activities of the Hungarian Organization for Patients with Immunodeficiencies (HOPI)

Horváth, Zs., Apáti-Nagy, M. (Debrecen)

Asociatia Romana a Pacientilor cu Imunodeficiente Primare (ARPIP)

Baldea, A. (Romania)

An undefined case of lymphadenopathy

Apostol, A., Ionescu, F. (Romania)

Another face of neutropenia

Bataneant, M., Preja, M., Civic, C., Lelik, M., Baica, M., Manzat, L., Serban, M. (Romania)

Common variable immunodeficiency – a clinically and biologically polymorphic disease

Bataneant, M., Cucuruz, M., Ionita, H., Baica, M., Lesovici, M., Botiz, A., Serban, M. (Romania)

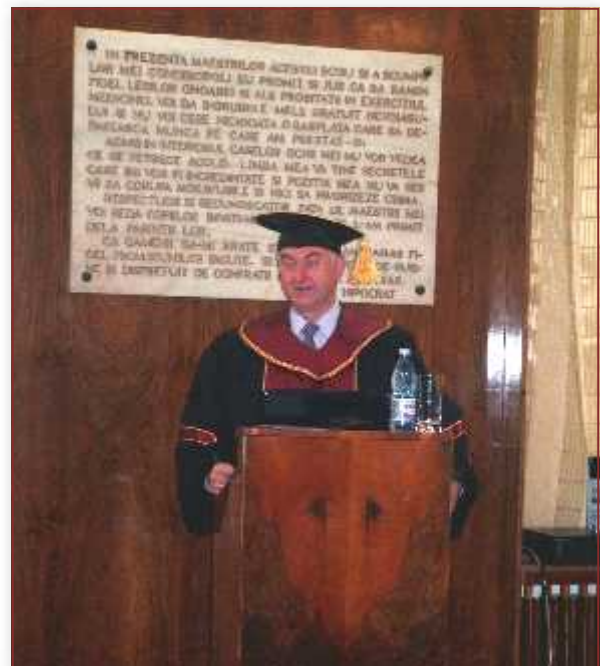
Ceremony of “Doctor Honoris Causa”



Members of the Senate of UMF “Victor Babes” and Professor Maródi



Professors Margit Serban and László Maródi



Professor Maródi is giving his talk after receiving the Honoris Causa degree

SUMMARY AND CONCLUSION

The 79th J Project symposium was organized in Timisoara, at the UMF “Victor Babes” University. As Timisoara is the national center for PID diagnostics and treatment in Romania, the meeting was attended by doctors from various regions of the country. Invited speakers from Debrecen and elsewhere discussed IL-17-mediated immunity in human newborns, the case of a new Wiskott-Aldrich syndrome patient diagnosed by the Timisoara and Debrecen group together, and a challenging case with neutropenia. Professors Serban and Gherghina gave introductory talks on PID diagnostics and X-linked agammaglobulinemia. Representatives of the Hungarian (HOPI) and Romanian (ARPIP) PID patients’ organizations also took active part at the meeting. The event was highlighted by the celebration of Prof. László Maródi who received Doctor Honoris Causa degree from the Senate of the UMF “Victor Babes” University.

Mihaela Bataneant

MINSK, BELARUS

November 17, 2012

Host: Mikhail Belevtsev (*Belevtsev_m@mail.ru*)

Venue: Belarusian Research Center for Pediatric Oncology, Hematology and Immunology

Main Topics:

1. Clinical aspects of primary immune deficiency disease
2. Immunological and molecular-genetic diagnostics of new primary immune deficiency
3. Modern approaches of treatment for patients with primary immune deficiency

PROGRAM

November 17

Primary immunodeficiency patient case in the Republic of Belarus.

Belevtsev, M. V. (Belarus)

B cells defects: Clinical aspects and laboratory diagnostics

Durandy, A. (France)

Syndromes of macrophage activation

Kondratenko, I. V. (Russia)

Autoinflammatory disorders in children: Clinical symptoms, incidence, diagnostics, genetics and treatment

Korsunskii, I. A. (Russia)

Syndromes of chromosomal instability: diagnostics and treatment

Vakhlyarskaya, S. S. (Russia)

Syndromes of hyper production of IgE: diagnostics and treatment

Deripapa, E. V. (Russia)

Replacement immunoglobulin therapy in children with primary antibody deficiency: subcutaneous injection as an alternative to intravenous

Uglova, T. A. (Belarus)

Immunoglobulins: what and when?

Pashchenko, O. E. (Russia)

Atypical presentation of SCID – diagnostics, clinical cases

Rodina, U. A. (Russia)

Immunological and genetics basis of atypical SCID

Sharapova, S. O. (Belarus)

Gastrointestinal symptoms in patients with PID

Savanovich, I. I. (Belarus)

Waldmann disease in clinical practice

Kuriane, N. N. (Latvia)

Shwachman–Diamond syndrome: Clinical case report

Prokofjeva, T. (Latvia)

The role of GATA-1 gene in development of hereditary thrombocytopenia.

Sokolova, N. E. (Russia)

Case from practice

Tuzankina, I. A. (Russia)

The case of generalized mycosis, caused by alternaria

Kletski, S. K. (Belarus)

Foundation of Ukrainian registry of primary immunodeficiency

Bondarenko, A. V. (Ukraine)

SUMMARY AND CONCLUSION

A conference on Primary Immunodeficiencies was organized in Minsk on November 17, 2012, within the framework of 80th J Project. More than 100 pediatricians and immunologists from all regions of Belarus and other countries, such as Russia, Ukraine, France, and Latvia participated at the conference. The leading experts of the Center Sharapova S. O, Belevtsev M. V., Uglova T. A. presented reports. As a result of center work, primary immunodeficiency was diagnosed in 155 patients, methods of advanced immunological diagnostics were introduced and genetic investigation on 21 genes was carried out. Irina Kondratenko, Anne Durandy, Irina Tuzankina, Anastasia Bondarenko, Tatiana Prokofjeva, Natalia Kuriane and other specialists also gave reports.

Mikhail Belevtsev



Participants at the Meeting

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

Venue: Regional Children Clinical Hospital

Main Topic: Diagnostics and management of children with primary immunodeficiencies

PROGRAM

November 23

Demonstration of a documentary “A right for life”

1. PIDs as orphan diseases.

Tuzankina, I. (Yekaterinburg, Institute of Immunology and Physiology, Regional Children’s Hospital)

2. PID Registry of Bashkortostan region.

Prolygina, D. (Ufa, Regional Children’s Hospital).

3. Clinical polymorphism of rare types of PID.

Pischalnikov, A. (Chelyabinsk, Chelyabinsk State Medical Academy).

4. Challenging cases from PID practice.
Tuzankina, I. (Yekaterinburg, Institute of Immunology and physiology, Regional children’s hospital)

5. Flow cytometry for evaluation of lymphocyte proliferation.
Hayrullina, R. (Bashkortostan State Medical University, Regional Children’s Hospital).

Case reports of patients with ataxia-telangiectasia and EBV-associated lymphoproliferative syndrome.



L–R: Rustem Ahmetshin, Raisa Hayrullina, Alexander Pischalnikov, Irina Tuzankina



SUMMARY AND CONCLUSION

Several J Project Meetings had been held in Urals region: Yekaterinburg, Chelyabinsk, Tyumen, and Perm. The venue of the next meeting was Ufa. About 200 participants took part in the meeting. The scientific program of the conference included reports of leading specialists of our region as well as showing a documentary called “The right for life”. Also there was a discussion on rare cases and a workshop section where parents of PID patients participated. Parents spoke about problems of PID care through their families’ experiences. The scientific and social program was rated as highly successful and we would like to thank all the participants, especially our speakers. There is no doubt that the J Project Meeting in Ufa was a very important scientific event in the field of primary immune deficiencies. We hope that it would contribute to brighter future of patients with PID.

Irina Tuzankina

SANLIURFA, TURKEY

November 25, 2012

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

Venue: Dedeman Hotel, Sanliurfa

Main Topic: Primary immunodeficiencies



PROGRAM

November 25

The awareness on primary immunodeficiency diseases

Reisli, İ. (Turkey)

The signs of PID in children

Cemalettin, D. Z. (Turkey)

The signs of PID in adults

Caliskaner, Z. (Turkey)

SUMMARY AND CONCLUSION

The frequency of primary immunodeficiency is high in Turkey due to higher ratio of consanguinity than in literature. We have to organize educational meetings in Eastern Anatolia, to increase the awareness of primary immunodeficiency diseases.

For this purpose, the second Eastern Anatolia J Project Meeting was held in Sanliurfa on November 25, 2012. The meeting was organized by the Departments of Pediatric Immunology and Allergy in the Medical School of Harran University and Necmettin Erbakan University.

The meeting was focused on the diagnosis of PID among the medical students, physicians and pediatricians, also to discuss the clinical symptoms and to clarify the importance of early diagnosis in PID. More than 50 participants attended the meeting. The meeting was started with an opening lecture by Prof. Ismail Reisli. He gave a lecture about the awareness of primary immune defects in Turkey. Afterwards, two lectures were given in the meeting which were based on clinical signs of PID in children and adults by Dr. Cemalettin and Prof. Çalışkaner, respectively.

I would like to thank all speakers and participants for their contributions and our sponsor (Gen İlaç) for the financial help which made it possible to organize this event.

Ismail Reisli

CRACOW, POLAND

December 1, 2012

Host: Anna Szaflarska (*miszafla6@wp.pl*)

Venue: Jagiellonian University, Auditorium Maximum

Main Topic: Clinical immunology and allergology

PROGRAM

December 1

Rutkowska Magdalena: The role and function of regulatory T cells

Siedlar, M. (Poland)

Hyper IgE syndrome: allergy, immunodeficiency or granulocyte defect?

Kowalczyk, D. (Poland)

Etiopathogenesis of humoral immunity defects.

Szaflarska, A. (Poland)

Allergy and autoimmunity in primary immunodeficiencies.

Pituch-Noworolska, A., Zwonarz, K., Blaut-Szlósarczyk, A. (Poland)

Autoimmunity in humoral immunodeficiencies.

Strach, M., Kieszowska, I. (Poland)

The influence of humoral immunity defects on activation and regulation of contact hypersensitivity in animal model.

Bryniarski, K. (Poland)

SUMMARY AND CONCLUSION

The J Project meeting held on 15 December, 2012 in Cracow (Poland) provided a splendid opportunity to share experience in the field of clinical immunology and allergology with its attendees who came from various centers in Poland.

The 6th Cracovian Symposium on Allergology and Clinical Immunology is organized under the auspices of the Jagiellonian University. The main organizer is the Polish Society for Allergy. This symposium results from cooperation between allergologists and immunologists. The first immunological session was simultaneously the 83rd J Project Meeting. Among participants of the symposium were allergologists, immunologists, pediatricians and internal medicine specialists. It is worth mentioning that the general practitioners and immunologists who took part at the adult allergy meeting, also participated at the J Project symposium.

Anna Szaflarska

J Project Meetings in Central and Eastern-Europe 2004–2012

1. **Targu Mures**, Romania, March 11–12, 2004; Organizer: Csilla Todea
2. **Prague**, Czech Republic, May 10–11, 2004; Organizer: Anna Sediva
3. **Belgrade**, Serbia and Montenegro, June 11–12, 2004; Organizer: Srdjan Pasic
4. **Skopje**, Macedonia, September 17–18, 2004; Organizer: Katarina Stavrik
5. **Kiev**, Ukraine, November 18–19, 2004; Organizer: Alla Volokha
6. **Zakopane**, Poland, December 16–18, 2004; Organizer: Ewa Bernatowska
7. **Sofia**, Bulgaria, April 15–16, 2005; Organizer: Elissaveta Naumova
8. **Prague**, Czech Republic, May 9–10, 2005; Organizer: Anna Sediva
9. **Gdansk**, Poland, September 23–24, 2005; Organizer: Ewa Bernatowska
10. **Debrecen**, Hungary, November 4–5, 2005; Organizer: László Maródi
11. **Lviv**, Ukraine, November 25, 2005; Organizer: Larysa Kostyuchenko
12. **Oradea**, Romania, December 18, 2005; Organizer: Zoltán Ellenés
13. **Debrecen**, Hungary, January 16, 2006; Organizer: László Maródi
14. **Prague**, Czech Republic, May 8–9, 2006; Organizer: Anna Sediva
15. **Bucharest**, Romania, June 9–10, 2006; Organizer: Nicolae Iagaru
16. **Minsk**, Belarus, November 9–10, 2006; Organizer: Mikhail Belevtsev
17. **Debrecen**, Hungary, December 7–8, 2006; Organizer: László Maródi
18. **Zaporizhzhya**, Ukraine, Apr 19–20, 2007; Organizer: Liudmyla Chernyshova
19. **St. Petersburg**, Russia, May 29–30, 2007; Organizer: Marina Guseva
20. **Ohrid**, Macedonia, September 20–21, 2007; Organizer: Kristina Mironska
21. **Iasi**, Romania, October 12–13, 2007; Organizer: Aurica Rugina
22. **Ljubljana**, Slovenia, November 16–17, 2007; Organizer: Tadej Avcin
23. **Odessa**, Ukraine, April 10, 2008; Organizer: Liudmyla Chernyshova
24. **Sunny Beach**, Bulgaria, May 22–23, 2008; Organizer: Elissaveta Naumova

25. **Sarajevo**, Bosnia-Herzegovina, October 10–11, 2008; Organizer: Velma Mulaosmanovic
26. **Chisinau**, Rep. of Moldova, Oct. 31–Nov. 1, 2008; Organizer: Lyudmila Cerempei
27. **Riga**, Latvia, November 27–28, 2008; Organizer: Tatjana Prokofjeva
28. **Timisoara**, Romania, March 19–20, 2009; Organizer: Margit Serban
29. **Sevastopol**, Ukraine, April 9–10, 2009; Organizer: Liudmyla Chernyshova
30. **Yekaterinburg**, Russia, May 13–14, 2009, Organizer: Irina Tuzankina
31. **St. Petersburg**, Russia, June 9–10, 2009; Organizer: Marina Guseva
32. **Konya**, Turkey, June 18–19, 2009; Organizer: Ismail Reisli
33. **Cracow**, Poland, September 24–25, 2009; Organizer: Danuta Kowalczyk
34. **Tallinn**, Estonia, October 7–8, 2009; Organizer: Sirje Velbri
35. **Ljubljana**, Slovenia, October 9–10, 2009; Organizer: Nataša Toplak
36. **Tehran**, Iran, October 11–12, 2009; Organizer: Asghar Aghamohammadi; Nima Rezaei
37. **Cairo**, Egypt, October 18–19, 2009; Organizer: Nermeen Galal
38. **Minsk**, Belarus, October 22–23, 2009; Organizer: Mikhail Belevtsev
39. **Tirana**, Albania, April 8–9, 2010; Organizer: Georgina Kuli-Lito
40. **Porto Marina**, Egypt, April 16–17, 2010; Organizer: Aisha El-Marshafy
41. **Kharkov**, Ukraine, May 19–20, 2010; Organizer: Liudmyla Chernyshova
42. **Zlatibor**, Serbia, June 1–2, 2010; Organizer: Srdjan Pasic
43. **Zagreb**, Croatia, July 2–3, 2010; Organizer: Darko Richter
44. **Chelyabinsk**, Russia, August 30–31, 2010; Organizer: Irina Tuzankina
45. **Budapest**, Hungary, September 9–10, 2010; Organizers László Maródi; Miklós Szolnoky
46. **Tehran**, Iran, October 11–12, 2010; Organizers: Asghar Aghamohammadi; Nima Rezaei
47. **Pushkin Hills**, Russia, February 3–4, 2011; Organizers: Marina Guseva; Areg Totolian
48. **Zakopane**, Poland, February 24–26, 2011; Organizer: Ewa Bernatowska
49. **Oradea**, Romania, March 1, 2011; Organizer: Ladislau Ritli
50. **Debrecen**, Hungary, March 10–11, 2011; Organizer: László Maródi
51. **Moscow**, Russia, March 31–April 1, 2011; Organizer: Irina Kondratenko
52. **Baku**, Azerbaijan, April 22–23, 2011; Organizer: Gulnara Nasrullayeva
53. **Bratislava**, Slovakia, April 28–29, 2011; Organizer: Peter Ciznar
54. **Lutsk**, Ukraine, May 11–12, 2011; Organizer: Liudmyla Chernyshova
55. **Sibiu**, Romania, June 10–11, 2011; Organizer: Sorin Iurian
56. **Chelyabinsk**, Russia, June 26–27, 2011; Organizer: Irina Tuzankina
J Project session Beijing, China, September 23, 2011; Organizer: Tina Lee
57. **Ohrid**, Rep. Macedonia, October 8, 2011; Organizer: Kristina Mironska
58. **Tehran**, Iran, October 15, 2011; Organizer: Nima Rezaei
59. **Trabzon**, Turkey, November 19–20, 2011; Organizer: Fazil Orhan; Ismail Reisli
60. **Riga**, Latvia, November 26, 2011; Organizer: Tatjana Prokofjeva
61. **Lillafüred**, Hungary, January 20–21, 2012; Organizer: Miklós Szolnoky
62. **Budapest**, Hungary, January 27–28, 2012; Organizer: Miklós Szolnoky; Judit Szabó

63. **Rostov-on-Don**, Russia, March 16, 2012; Organizer: Ludmila Sizyakina
64. **Moscow**, Russia, March 29, 2012; Organizer: Irina Kondratenko
65. **Chernigov**, Ukraine, April 5–6, 2012; Organizer: Liudmyla Chernyshova
66. **Tallinn**, Estonia, April 19, 2012; Organizer: Krista Ress
67. **Tehran**, Iran, April 22, 2012; Organizers: Asghar Aghamohammadi; Nima Rezaei
68. **Bratislava**, Slovakia, April 27, 2012; Organizers: Peter Ciznar
69. **Diyarbakir**, Turkey; May 12, 2012; Organizer: Ismail Reisli
70. **Prague**, Czech Republic; May 14–15, 2012; Organizer: Anna Sediva
71. **Konya**, Turkey; May 26–27, 2012; Organizer: Ismail Reisli
72. **Warsaw**, Poland;; 2012; Organizer: Ewa Bernatowska
73. **Sibiu**, Romania; June 1–2, 2012; Organizer: Sorin Iurian
74. **Tzigov Chark**; June 8–9, 2012; Organizer: Elissaveta Naumova
75. **Astana City**, Kazakhstan, June 12–15, 2012; Organizer: Nurzhan Otarbayev
76. **Tyumen**, Russia-Siberia, July 2, 2012; Organizer: Irina Tuzankina
77. **Ljubljana**, Slovenia, September 14–15, 2012; Organizer: Tadej Avcin
78. **Tehran**, Iran, October 13–14, 2012; Organizer: Nima Rezaei
79. **Timisoara**, Romania, October 25–26, 2012; Organizer: Mihaela Bataneant
80. **Minsk**, Belarus, November 17, 2012; Organizer: Mikhail Belevtsev
81. **Ufa**, Russia, November 23, 2012; Organizer: Irina Tuzankina
82. **Sanliurfa**, Turkey, November 25, 2012; Organizer: Ismail Reisli
83. **Cracow**, Poland, December 15, 2012; Organizer: Ewa Bernatowska

Scheduled J Project Meetings in 2013 N° 84–

<i>City (Country)</i>	<i>Organizer (s)</i>	<i>Date</i>
84. Mukachevo (Ukraine)	Liudmyla Chernyshova <i>luchernyshova@yandex.ua</i>	April 18
85. Ljubljana (Slovenia)	Tadej Avcin <i>tadej.avcin@gmail.com</i>	April (date TBA)
86. Bratislava (Slovakia)	Peter Ciznar <i>ciznar@dfnsp.sk</i>	April 24
87. Debrecen (Hungary)	László Maródi <i>lmarodi@med.unideb.hu</i>	April 25
88. Erzurum (Turkey)	Ismail Reisli <i>ireisli@hotmail.com</i>	April 27
89. Prague (Czech Republic)	Anna Sediva <i>Anna.Sediva@fnmotol.cz</i>	May 13–14
90. Moravia (Czech Republic)	Jiri Litzman; Anna Sediva <i>jiri.litzman@fnusa.cz</i> <i>Anna.Sediva@fnmotol.cz</i>	May 30–31
91. Budapest (Hungary)	László Maródi <i>lmarodi@med.unideb.hu</i>	May 31–June 1

92. Sibiu (Romania)	Iurian Sorin <i>iurian_sorsab@hotmail.com</i>	June 7–8
93. Ljubljana (Slovenia)	Tadej Avcin <i>tadej.avcin@gmail.com</i>	September (date TBA)
94. Cracow (Poland)	Ewa Bernatowska <i>bernatowskae@yahoo.com</i>	September 20–21
95. Malatya (Turkey)	Ismail Reisli <i>ireisli@hotmail.com</i>	September 28
96. Tehran (Iran)	Nima Rezaei <i>rezaei_nima@yahoo.com</i>	October (date TBA)
97. Krasnoyarsk (Siberia, Russia)	Irina Tuzankina <i>ituzan@yandex.ruc</i>	October (date TBA)

THE J PROJECT

Steering Committee Members

1. Albania	Tirana	Georgina Kuli-Lito
2. Azerbaijan	Baku	Gulnara Nasrullayeva
3. Belarus	Minsk	Mikhail Belevtsev
4. Bosnia-Herzegovina	Sarajevo	Velma Mulaosmanovich
5. Bulgaria	Sofia	Elissaveta Naumova
6. Croatia	Zagreb	Darko Richter
7. Czech Republic	Prague	Anna Sediva
8. Czech Republic	Brno	Jiri Litzman
9. Egypt	Cairo	Aisha El-Marshafy
10. Estonia	Tallinn	Sirje Velbri
11. Estonia	Tallinn	Krista Ress
12. Hungary	Debrecen	László Maródi
13. Hungary	Debrecen	Melinda Erdős
14. Hungary	Debrecen	Beáta Tóth
15. Hungary	Budapest	Miklós Szolnok
16. Iran	Tehran	Asghar Aghamohammadi
17. Iran	Tehran	Nima Rezaei
18. Kazakhstan	Astana City	Nurzhan Otarbayev
19. Kazakhstan	Astana City	Panteley Popandopulo
20. Latvia	Riga	Tatjana Prokofjeva
21. Lithuania	Kaunas	Brigita Sitkauskiene
22. Poland	Warsaw	Ewa Bernatowska
23. Poland	Warsaw	Malgorzata Pac
24. Poland	Warsaw	Malgorzata Skomska
25. Poland	Cracow	Anna Szaflarska
26. Rep. of Macedonia	Skopje	Kristina Mironska
27. Rep. of Moldova	Chisinau	Liudmyla Cerempei

28. Romania	Bucharest	Ioan Gherghina
29. Romania	Timisoara	Mihaela Bataneant
30. Romania	Timisoara	Margit Serban
31. Romania	Sibiu	Sorin Iurian
32. Russia	Moscow	Irina Kondratenko
33. Russia	St. Petersburg	Marina Guseva
34. Russia	Chelyabinsk	Alexandr Pischalnikov
35. Russia	Yekaterinburg	Irina Tuzankina
36. Serbia	Belgrade	Srdjan Pasic
37. Slovakia	Bratislava	Peter Ciznar
38. Slovenia	Ljubljana	Tadej Avcin
39. Turkey	Konya	Ismail Reisli
40. Ukraine	Kiev	Liudmyla Chernyshova
41. Ukraine	Kyiv	Anastasia Bondarenko
42. Ukraine	Lviv	Larysa Kostyuchenko
43. Ukraine	Kiev	Alla Volokha

Genetic testing in the Debrecen PID Center

PRIMARY IMMUNODEFICIENCIES (*Genes*)

1. X-linked agammaglobulinemia (*BTK*)
2. Common variable immunodeficiency subtype 1 (*ICOS*)
3. Common variable immunodeficiency subtype 2 (*TACI*)
4. X-linked hyper-IgM syndrome (*TNSF5=CD40L*)
5. Hyper-IgM syndrome (*UNG*)
6. Activation induced cytidine deaminase deficiency (*AICDA*)
7. Recombination-activating gene 1 deficiency (*RAG1*)
8. Recombination-activating gene 2 deficiency (*RAG2*)
9. X-linked severe combined immunodeficiency (*SCIDX1*) (*IL-2RG*)
10. X-linked chronic granulomatous disease (*CYBB*)
11. Autosomal recessive chronic granulomatous disease (*NCF1*)
12. Wiskott-Aldrich syndrome (*WAS*)
13. AR-Hyper-IgE syndrome (*TYK2*)
14. AD-Hyper-IgE syndrome (*STAT3*)
15. Severe congenital neutropenia type 1 (*ELANE*)
16. Severe congenital neutropenia type 2 (*GFII*)
17. Severe congenital neutropenia type 3 (*HAX1*)
18. Severe congenital neutropenia type 4 (*G6PC3*)
19. Hereditary neutrophilia (*CSF3R*)
20. Shwachman-Diamond syndrome (*SBDS*)
21. Familial hemophagocytic lymphohistiocytosis syndromes (*PRF1*)
22. Warts, hypogammaglobulinemia, infections and myelokathexis (*WHIM*) (*CXCR4*)

23. Complement component 2 deficiency (*C2*)
24. X-linked lymphoproliferative syndrome (*SH2D1A*)
25. X-linked lymphoproliferative syndrome type 2 (*XIAP*)
26. DOCK8 deficiency (*DOCK8*)
27. Nijmegen breakage syndrome (*NBN*)
28. Chronic mucocutaneous candidiasis disease – DC-SIGN (*CLEC4L*)
29. Chronic mucocutaneous candidiasis disease – dectin-1 (*CLEC7A*)
30. Chronic mucocutaneous candidiasis disease – dectin-2 (*CLEC6A*)
31. Chronic mucocutaneous candidiasis disease (*MRC1*)
32. Chronic mucocutaneous candidiasis disease (*CARD9*)
33. Chronic mucocutaneous candidiasis disease (*STAT1*)
34. Chronic mucocutaneous candidiasis disease (*IL17RA*)
35. Chronic mucocutaneous candidiasis disease (*IL17F*)
36. Cartilage hair hypoplasia (*RMRP*)
37. X-linked Dyskeratosis congenita (*DKC1*)
38. Autoimmune lymphoproliferative syndrome type 1A (*CD95=FASG*)
39. Autoimmune lymphoproliferative syndrome type 1B (*CD178=FASLG*)
40. Autoimmune polyendocrine syndrome (*AIRE*)
41. Hyper-IgD syndrome (*MVK*)
42. IL18R1 deficiency (*IL18R1*)
43. X-linked ectodermal dysplasia, incontinentia pigmenti (*IKBKG*)
44. Familial Mediterranean fever (*MEFV*)
45. Mendelian susceptibility to mycobacterial disease (*IL12RB1*)
46. Mendelian susceptibility to mycobacterial disease (*IL12B*)
47. Mendelian susceptibility to mycobacterial disease (*IFNGR1*)
48. Mendelian susceptibility to mycobacterial disease (*IFNGR2*)
49. MYD88 deficiency (*MYD88*)

LYSOSOMAL STORAGE DISEASES (*Genes*)

50. Fabry disease (*GLA*)
51. Gaucher disease (*GBA*)
52. Niemann-Pick Disease (*SMPD1*)

OTHER DISEASES (*Genes*)

53. Von Hippel-Lindau Syndrome (*VHL*)
54. X-linked adrenal hypoplasia congenital (*DAX1*)
55. Galectin 3 deficiency (*LGALS3*)
56. Alström syndrome (*ALMS1*)
57. Atopic eczema (*FLG*)



Beáta Tóth, Debrecen

Links

**Eastern and Central European Infectious and Pediatric
Immunology Center for Training and Research (ECE-IPI-CTR)**

<http://ece.dote.hu>

The J Project (JP)

<http://jproject.dote.hu>

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>