The J Project
2008

J Countries

eceipi
EAST-CENTRAL-EUROPEAN INFECTIOUS AND PEDIATRIC IMMUNOLOGY CENTRE FOR TRAINING AND RESEARCH
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Genes available for genetic testing in the Debrecen Jeffrey Modell PID Reference Center
Foreword

The mission of The J Project is to be the forum in East-European countries to increase awareness, and to improve diagnostic facilities and complex management of primary immunodeficiencies.

Since the first J Project meeting in Targu Mures, Romania, on March 11-12, 2004, more and more in the field have been actively working to achieve these goals. It is amazing that in the beginning of 2007 we have not only scheduled six J Project meetings for the year, but have already defined the venue of one of the 2008 events (Bulgaria). Detailed information on programs, conclusions, and the atmosphere of these Meetings are described in the annual J Project booklets as well as on the web (www.ece.dote.hu).

The year of 2006 was highlighted by several events to remember by the primary immunodeficiency community. Just to mention a few, in June an EU PID consensus conference was organized in the Paul-Erlich-Institute, Langen, Germany (pp…). This Meeting was a milestone in the long term awareness campaign on PIDs ESID, IPOP! INGID, EFIS among the general public. In October, Budapest saw the biannual ESID/IPOP!INGID meeting, the summary of which was published not only in the ESID newsletter, but also by Nature Immunology (8:323,2007) indicating the unique achievements made by scientists who participated at the Meeting. Further, the first gene therapy trial in patients with Wiskott-Aldrich syndrome was started at the University of Hanover, Germany (pp..) increasing the number of PIDs in which gene therapy was initiated.

The J Project events in 2006 covered a wide range of diagnostic and therapeutical aspects of PID patient care. We started in Debrecen with a discussion on current status, and future challenges in gene therapy in Wiskott-Aldrich syndrome (pp…). The traditional Prague Spring Meeting was focused in this year on new primary immunodeficiency disorders (pp…). The first J Project meetings in Bucharest and Minsk were organized in June and November, respectively, and attracted a large number of immunologist, infectious disease specialists, hematologists, transplant physicians, and others with an interest in PID from both South-Romania and Belarus. These meetings were primarily physicians’ education events, but also provided opportunity to discuss recent diagnostic and treatment achievements in these large areas of East-Europe. The perspective of PID gene sequencing in Minsk, Belarus was discussed and collaboration to this end with the Debrecen Jeffrey Modell Center was decided on. The meeting series in 2006 ended up in Debrecen with a summary of PID mutation database in East-Europe. I am grateful to all who have joined this Project and take the opportunity to thank to the Jeffrey Modell Foundation and Biotest Hungary Kft, our major sponsors.


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

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

The Centre provides modern educational utilities, demonstrational materials, and rooms that are suitable for practical seminars as well as lecture rooms. ECE IPI CTR functions as an institutional and regional Infectious and Pediatric Immunology Centre. Its essential role is the initiation of regular postgraduate courses for specialists in Infectious Diseases and Immunology in countries of East Europe.

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

PID Awareness Meetings in 2008

CITY, Country | DATE
--- | ---
1. ODESSA, Ukraine | 10 April, 2008
2. SUNNY BEACH, Bulgaria | 22-23 May, 2008
3. SARAJEVO, Bosnia-Herzegovina | 10-11 October, 2008
4. CHISINAU, Republic of Moldova | 31 October – 1 November, 2008
5. RIGA, Latvia | 27-28 November, 2008

Aims

1. To organize professional meetings on PID and related diseases in regions of East-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.
Host:
Liudmyla Chernyshova (chernyshova@ukr.net)

Venue:
Hotel Valentina, Franzuzsky Bulvar, Odessa

Main Topic:
Diagnostics and management of children with primary immunodeficiency diseases
PROGRAM

April 10

Opening ceremony

Welcome from:
Ministry of Health of Ukraine and
Department of Health Care of Odessa

The evolving J Project
Maródi L. (Debrecen)

Medical management of children with
primary immunodeficiency
Chernyshova L. (Kiev)

Characteristics of B-lymphocyte phenotypes
in patients with PIDs
Volokha A. (Kiev)

PIDs with chromosomal instability
Kostyuchenko L. (Lviv)

Coffee break

Combined immunodeficiency
Samarin D. (Kiev)

Diagnostics and treatment of children with
PID in Russia
Prodeus A. (Moscow)

PID patient care in Latvia
Prokofjeva T. (Riga)

Vaccination in immunocompromised
children
Goldstein O. (Moscow)

Hematopoietic stem cell transplantation in
patients with SCID
Balashov D. (Moscow)

PID case presentations
Mirzoyants G. (Odessa)

Dinner

Indications and safety of vaccination in PID
children
Lapiy F. (Kiev)

Management of patients with chronic
granulomatosis disease
Guseva M., Davydova N. (St. Petersburg)

PID diagnostics in Moldova
Cerempei L. (Chishinau)

PID Patients/Parents group session

Closing ceremony
SUMMARY AND CONCLUSIONS

Up to date three J Project seminars were held in Ukraine - in Kiev (2004), in Lvov (2005), and in Zaporozhye (2007). By this way the central, western, and eastern regions of Ukraine were involved into the J Project program. The place of 4th J Project Meeting in Ukraine was in Odessa.

Odessa – is a large city and seaport on the Black Sea shore, which is situated on the south of Ukraine. The population of this region is about 2 million people. The Odessa region has a low diagnostic rate of PIDs because of the insufficient information level of pediatricians about primary immunodeficiencies.

Connecting to the scientific program the Meeting also included a workshop section where parents of PID children participated. Parents spoke about the problems in PID care through their families’ examples. Their speeches have impressed the audience and touched everybody’s heart.

The social program included a City Tour and attending of the Odessa Opera Theatre. The sponsors of the event were Sanofi-Pasteur (France) and Biofarma (Ukraine) companies.

Liudmyla Chernyshova

Alla Volokha, ?, Fedir Lapiy, ?, ?

Liudmyla Chernyshova and László Maródi

?, ?, Liudmyla Chernishova, and Alla Volokha
Sunny Beach, Bulgaria
22-23 May, 2008

Host:
Elissaveta Naumova (immun@sun.medun.acad.bg)
Guergana Stoyanova (gal_ps@yahoo.co.uk)

Venue:

Main Topic:
23 May, Friday

Opening
Naumova E (Sofia)

The J project – overview
Maródi L. (Debrecen)

ESID Registry
Kindle G. ()

Bulgarian national PID registry – problems needed to be solved
Petrova G. ()

Molecular defects associated with PIDs
Naumova E. (Sofia)

Flowcytometry in the diagnostic evaluation of PID
Baltadjieva D. ()

Molecular and clinical characteristics of patients with Wiskott-Aldrich syndrome in Hungary
Maródi L. (Debrecen)

Case report: IgA deficiency in a 12 year old girl
Stoeva T. ()

Case report: Idiopathic CD4 immunodeficiency – how can we deal with it
Penkova K. ()

Immunoglobulin therapy
Perenovska P. ()

Immunomodulators in immunodeficiency (Ewopharma)

Case report
Baleva M. ()
SUMMARY AND CONCLUSIONS

Elissaveta Naumova
Sarajevo, Bosnia-Herzegovina
October 10-11, 2008

Host:
Velma Mulaosmanovic (velmamulaosmanovic@hotmail.com)

Venue:
Department of Allergology, Rheumatology and Clinical Immunology, Children's Hospital Sarajevo, University Clinical Center/Pediatric Educational Center Sarajevo (PECS)

Main Topic:
Early diagnosis and therapy of primary immunodeficiencies
PROGRAM

10 October, Friday

Early recognition of PID

Opening
Mesihović-Dinarević S. Director of Children's Hospital/Pediatric Educational Center Sarajevo

Introduction
Mulaosmanović V. (Sarajevo)

The J Project: achievements and current concepts
Maródi L. (Debrecen)

Classification and PID research in Europe
Mulaosmanović V. (Sarajevo)

Ten warning signs of PID
Delihasanović I. (Sarajevo)

Coffee break

Assessment of PID

Laboratory evaluation of T and B cell deficiencies
Zečević L., Karmehić J. (Sarajevo)

Laboratory evaluation of the phagocyte system
Šarac-Delić M., Drač Z., Karmehić J. (Sarajevo)

Genetic basis and diagnostics of PIDs
Kapur L. (Sarajevo)

Periodic fever syndrome
Toplak N. (Ljubljana)

Risk of malignancy development in patients with PID
Tunić A. (Sarajevo)

Coffee break

Treatment of PID

Bone marrow transplantation and gene therapy for primary immunodeficiency diseases
Seger R. (Zurich)

Use of human immunoglobulin in pediatrics
Džđarević A. (Sarajevo)

Vaccination of immunodeficient patients
Mulaomerović M. (Sarajevo)

11 October, Saturday

PID syndromes I

Clinical and genetic characteristics of Hemophagocytic Lymphohistiocytosis /Macrophage Activation Syndrome
Avčin T. (Ljubljana)

Clinical and genetic characteristics of Job syndrome
Maródi L. (Debrecen)

The cardiac-immunologic aspect of DiGeorge syndrome
Mesihović-Dinarević S. (Sarajevo)

Severe combined immunodeficiency and RAG deficiency phenotypes
Pašić S. (Belgrade)

Coffee break

PID syndromes II

Immune Dysregulation, Polyendocrinopathy, Enteropathy and X-linked inheritance (IPEX)
Gambineri E. (Firenze)

Case report: steps to diagnose autoimmune lymphoproliferative syndrome
Mulaosmanović V. (Sarajevo)

Bruton's agammaglobulinemia – case report
Tanović-Rujanac S., Mulaosmanović V. (Sarajevo)

Chediak-Higashi syndrome: yes or no? – case report
Čengić A., Mulaosmanović V. (Sarajevo)
SUMMARY AND CONCLUSIONS

On October 10-11, 2008, the J Project Primary Immunodeficiency Diseases (PID) Awareness Meeting was held in Sarajevo, Bosnia and Herzegovina. The meeting was organized by the recently founded Department of Allergology, Rheumatology and Clinical Immunology of the Children's Hospital, University Clinical Center Sarajevo in collaboration with the East-Central-European Infectious and Paediatric Immunology (ECE-IPI) Center for Training and Research and PID Care in Development Working Party of the European Society for Immunodeficiencies. This was the first time, that we had PID meeting in B&H. The meeting was attended by participants from several countries including Slovenia, Switzerland, Hungary, Serbia and Bosnia and Herzegovina.

The J Project Meeting in Sarajevo was entitled like the previous one held in November 2007 in Ljubljana, Slovenia: „Early Diagnosis and Treatment of Primary Immunodeficiency Diseases“. The keynote speaker was Prof. Dr Reinhard Seger from the University Children's Hospital Zürich, Switzerland who presented an excellent overview of current progress in bone marrow transplantation and gene therapy for PID. Prof. L. Maródi (Debrecen, Hungary) gave an interesting overview about the J Project achievements and current concepts. In addition, a number of invited and local speakers presented and discussed specific aspects of PID. The official language of the J Project Meeting in Sarajevo was English and Bosnian/Croatian/Serbian in order to foster discussions among participants from different countries and local ones.

The scientific program was divided in sessions as follows: 1) Early recognition of PID; 2) Assessment of PID, 3) Treatment of PID; 4) PID syndromes I, 5) PID syndromes II. Aims of the meeting were to increase public awareness, to increase and broaden knowledge of PID, to establish professional collaboration with other centers, to facilitate early diagnosis and treatment, to encourage establishment of patient support group and the main aim was to improve patient care. Desired concept of the meeting was completely fulfilled - collegial discussion in friendly atmosphere about certain and suspected diagnosis of PID patients and best therapy, emphasizing Education, Sociability and Interaction for all. Main problems that we are facing with in B&H, were well and easily defined: professional education (all levels), under diagnosed number of PID patients and low laboratory facilities. In particular, the J Project Meeting provided an initiative to establish the B&H multidisciplinary team for PID. Moreover, the J Project Meeting in Sarajevo provided an excellent opportunity to promote international collaboration in the field of PID among Central and South-Eastern European countries.

The scientific and social program of the meeting was rated as highly successful and we would like to thank all the participants, especially our distinguished invited speakers, including Prof. L. Maródi (Debrecen), dr. T. Avčin (Ljubljana) and dr. S. Pašić (Serbia) for their contribution. We thank our sponsors (ECE-IPI, Alkaloid, Roche, Unifarm, Medis, Pfizer) for their support. In addition, we would like to thank Prof. S. Mesihović-Dinarević, Director of the Children's Hospital Sarajevo, Prof. L. Maródi, Chair of the ECE-IPI Center for Training and Research for their continuous support and help with the organization of the meeting. Special thanks to dr Tadej Avčin, Children's Hospital Ljubljana for all his support, for making us scientifically impressed with Primary Immunodeficiency Disease world and for sharing knowledge with us.
There is no doubt that *J Project PID* Meeting in Sarajevo was a very important scientific event in the field of the pediatric primary immunodeficiency in B&H in 2008. We sincerely hope that it would contribute to brighter future for patients with PID.

Velma Mulaosmanović

In front: László Maródi, Velma Mulaosmanovic, Tadej Avcin, and Reinhard Seger
Chisinau, Rep. of Moldova
31 October–1 November, 2008

Host:
Lyudmila Cerempei (lcerempei@rambler.ru)

Venue:
Primary State Medical and Pharmaceutical University Nicolae Testemitanu

Main Topic:
Primary Immunodeficiencies in children: diagnostic and treatment problems
PROGRAM

31 October, Friday

Courses of the Continuous Medical Education

Basics of the immune response
Cerempei L. (Chisinau)

Primary and secondary immunodeficiency
Cerempei L. (Chisinau)

Chromosomal aberration syndromes: ataxia, telangiectasia and the Niimegen-breakage syndrome
Secara V. (Chisinau)

Common variable immunodeficiency
Schitco O. (Chisinau)

Severe combined immunodeficiency
Gorbunov G. (Chisinau)

Actualities in the treatment of children with primary immunodeficiency
Dumitras S. (Chisinau)

Vaccination in special conditions
Cerempei L. (Chisinau)

Coffee break

Clinical cases of children with defective WAS protein expression
Zueva (St. Petersburg)

Immunotherapy in asthma
Sinitchi G. (Iasi)

Secondary immune disorders – background for ecological diseases in children
Vasilos L., Cojocaru A. (Chisinau)

Diagnosis and treatment of children with PID in Lithuania
Procofieva T. (Riga)

Primary X-linked immunodeficiency
Rugina A. Gotea S., Moraru E., Murgu A., Alexoae M. (Iasi)

Lunch

Bruton’s disease – case report
Sciuca S. (Chisinau)

Extrinsic allergic alveolitis
Sinitchi G. (Iasi)

PID cases in Moldova
Sinitin L. (Chisinau)

Cardiovascular disorders in children with primary immunodeficiency
Stamati A. (Chisinau)

Actualization of the PID diagnosis in children in Moldova and National Register for primary immunodeficiency
Cerempei L. (Chisinau)

Discussion, conclusions
SUMMARY AND CONCLUSIONS

The XXVI^th^ Symposium of the international J Project program was organized in Chisinau, Republic of Moldova on 31st of October – 1st of November, 2008. The main topic of this symposium was: “Primary Immunodeficiencies in children: diagnostic and treatment problems”.

The meeting was assured by the Ministry of Health of Moldova, and the Chair of Pediatrics and Neonatology of the State Medical and Pharmaceutical University “Nicolae Testemitanu”.

The aim of the symposium was to get family practitioners and pediatricians acknowledged of the problems encountered with the diagnosis and treatment of patients with PIDs in Moldova. The symposium was attended by 345 medical doctors from national and inner city hospitals, and physicians from the primary health care level in rural areas were also participated.

The guest lecturers of this meeting were: Prof. László Maródi, Head of the “J Project”, and Head of the Department of Infectious and Pediatric Immunology, University of Debrecen (Debrecen, Hungary); Prof. Natalia Kalinina, Head of the Immunology Center of the Ministry for Emergency Situations (St. Petersburg, Russia); Prof. Georgeta Sinitchi, Head of the Department of Immunology and Allergy, and Head of the Department of Family Medicine, Medical and Pharmaceutical University “Gr.T. Popa” (Iasi, Romania); dr. Marina Guseva, Coordinator of the “J Project” (St. Petersburg, Russia); and dr. Tatiana Procofieva, Coordinator of the “J Project” (Riga, Latvia).

Prof. Maródi visited the National Hospital for Children “Emilian Cotaga” where he took part in a discussion, there an interesting case report of a patient with neutropenia was discussed. After the presentation the general recommendations were to examine the bone marrow and to find the possibilities for molecular diagnostic procedure.

Lyudmila Cerempei
Host:
Tatjana Prokofjeva (monja@balticom.lv)

Venue:
VEF Cultural Palace, Riga, Latvia

Main Topic:
Update on Primary Immunodeficiencies
PROGRAM

November 28

The J Project
Maródi L. (Debrecen)

Prokofieva T. (Riga)

Immunological and genetic diagnostics of primary immunodeficiencies in Belarus
Belevtsev M. (Minsk)

Clinical presentation and immunopathology of hyper-IgE syndrome
Maródi L. (Debrecen)

New therapy technologies in infected and post hypoxic heart pathologies in child
Degtjarova J. (Moscow)

Case report: a patient with hyper-IgE syndrome
Guseva M. (St. Petersburg)

PID: Major clinical manifestations and therapy principles.
Kondratenko I. (Moscow)

Primary antibody deficiencies in Estonia.
Sirje V. (Tallinn)

Overview of PID patient care in Latvia.
Prokofieva T. (Riga)

T-B+NK+ SCID case report
Eglite I. (Riga)

Case report: Generalized BCG-infection in SCID
Skangale A. (Riga)

Diagnostic problems in patients with T-cell deficiency, elevated IgE, reduced IgG, parathyroid deficiency, and cardiomyopathy
Prokofjeva T. (Riga)

Chronic mucocutaneous candidiasis
Shabashova (St. Petersburg)

Inherited heart diseases: frequency, treatment achievements and registration
Ilyin V. (Moscow)

Case report: hyper-IgM1 syndrome.
Lagzdinya D. (Riga)

Common variable immunodeficiency in a girl with exsudative pleuritis and recurrent maxillary sinusitis
Cirule I. (Riga)

Common variable immunodeficiency in a girl with diabetes mellitus
Kirilova I. (Riga)

Case report: chronic granulomatous disease
Prokofjeva T. (Riga)

Clinical approach to selective IgA deficiency in children
Purinya S. (Riga)

Case report: Ataxia-telangiectasia
Lindenberga S. (Riga)

T-cell lymphoma in a child with Nijmegen-breakage syndrome
Voitovich I. (Riga)

First registered case of Wiskott-Aldrich syndrome in Latvia
Medne G. (Riga)

Transient hypogammaglobulinemia in infancy
Puchuka Z. (Riga)

General discussion
SUMMARY AND CONCLUSIONS

In November 2008 the first J Project meeting was held in Riga, Latvia. The meeting was organized by the Latvian Immunology Society and the Latvian Pediatric Society.

Latvia is a small country near the Baltic Sea with a population of less than 2.2 million people. Among the 33 members of the Latvian Immunology Society (whom 15 are biologists) only one treats patients with PIDs. Because of the limited capabilities of the laboratories diagnosing PIDs in Latvia, to establish the correct diagnosis is sometimes very difficult. Latvia does not have national PID register and PID professional working groups.

The main aims of the meeting were to improve awareness of PID among the pediatricians and other specialists, and to discuss the diagnostic aspects, clinical symptoms and treatment of PIDs. The meeting was attended by 470 participants including pediatricians, immunologists, neonatologists and infectologists from all regions of Latvia. The guest lecturers of the meeting were prof. L. Maródi (Debrecen), M. Belevtsev (Minsk), prof. N. Shabashova and M. Guseva (St. Petersburg), prof. V. Ilyin and J. Degtjarova (Moscow), prof. L. Cerempei (Chisinau), and V. Sirje (Tallinn).

The first session of meeting was focused on the newest informations about the J Project program. In the first part an overview of the XII th ESID Meeting in ‘s-Hercogenbosh, the Netherlands was also presented. M. Belevtsev from the Belarus Research Center for Pediatric Oncology and Hematology (Minsk) reported on immunological and genetics diagnostic possibilities of PIDs in Belarus. Prof. L. Cerempei (Rep. of Moldova), S. Velibri (Estonia), and T. Prokofjeva also presented the organization of diagnostics and treatment of patients with PID in their countries. Prof. L. Maródi (Debrecen) gave a summary about the clinical presentation and immunopathology of the hyper-IgE syndrome. M. Guseva (St. Petersburg) presented an interesting case report about a patient with hyper-IgE syndrome.

The second part of the meeting contains a series of presentations from the local speakers about SCID and CVID. Prof. N. Shabashova from the Institute of Medical Mycology, Medical Academy of Postgraduate education (St. Petersburg) gave an interesting lecture about chronic mucocutaneous candidiasis. A case report about a family with hyper-IgM syndrome was also presented. The genetic diagnosis in this family was made in a collaboration with the Debrecen Jeffrey Modell PID Reference Center.

In the third part of the meeting the clinical presentations of a patient with chronic granulomatosis disease, a patient with Nijmegen-breakage syndrome associated with T-cell lymphoma, and presentation of the first registered patient with Wiskott-Aldrich syndrome in Latvia demonstrated our own experiences in this field.

The social events included a visit to the Old Town of Riga and the Lido Recreation Centre. We would like to thank all the participants who contributed to the succes of the first J Project meeting in Latvia. We hope that the experiences of this meeting will undoubtedly improve the situation of diagnostics and management of patients with primary immunodeficiency in Latvia.

In summary we think that J Project is an essential and important program especially for small countries with limited financial resources. The collaborations with the East-Central-European Infectious and Pediatric Immunology Centre for Training and Research, Debrecen, Hungary and others give us possibilities to improve the level of the diagnostics of primary immunodeficiencies in Latvia. We hope we are looking forward a successful cooperation in the next years.

Tatjana Prokofjeva
The Old Town of Riga
# J Project Meetings in 2009 No 28-40

<table>
<thead>
<tr>
<th>City (country)</th>
<th>Organizer</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. Timisoara (Romania)</td>
<td>Margit Serban <a href="mailto:mserban@rdstm.ro">mserban@rdstm.ro</a></td>
<td>March 19-20</td>
</tr>
<tr>
<td>29. Sevastopol (Ukraine)</td>
<td>Liudmyla Chernyshova <a href="mailto:chernyshova@ukr.net">chernyshova@ukr.net</a></td>
<td>April 09-10</td>
</tr>
<tr>
<td>30. Prague (Czech Republic)</td>
<td>Anna Sediva <a href="mailto:Anna.Sediva@fnmotol.cz">Anna.Sediva@fnmotol.cz</a></td>
<td>May 11-12</td>
</tr>
<tr>
<td>31. Ekaterinburg (Russia)</td>
<td>Irina Tuzankina <a href="mailto:I.Tuzankina@iip.uran.ru">I.Tuzankina@iip.uran.ru</a></td>
<td>May 13-14</td>
</tr>
<tr>
<td>32. St. Petersburg (Russia)</td>
<td>Marina Guseva <a href="mailto:gusevamarina@mail.ru">gusevamarina@mail.ru</a></td>
<td>June 9-10</td>
</tr>
<tr>
<td>33. Konya (Turkey)</td>
<td>Ismail Reisli <a href="mailto:ireisli@hotmail.com">ireisli@hotmail.com</a></td>
<td>June 25-26</td>
</tr>
<tr>
<td>34. Cracow (Poland)</td>
<td>Danuta Kowalczyk <a href="mailto:dkowalcz@cm-uj.krakow.pl">dkowalcz@cm-uj.krakow.pl</a></td>
<td>September 24-25</td>
</tr>
<tr>
<td>35. Tallin (Estonia)</td>
<td>Sirje Velbri <a href="mailto:velbrisir@hotmail.com">velbrisir@hotmail.com</a></td>
<td>October 7-8</td>
</tr>
<tr>
<td>36. Ljubljana (Slovenia)</td>
<td>Nataša Toplak <a href="mailto:natasa.toplak@ardi.si">natasa.toplak@ardi.si</a></td>
<td>October 9-10</td>
</tr>
<tr>
<td>37. Tehran (Iran)</td>
<td>Asghar Aghamohammadi <a href="mailto:aghamohammadi@sina.tums.ac.ir">aghamohammadi@sina.tums.ac.ir</a> and Nima Rezaei <a href="mailto:rezaei_nima@yahoo.com">rezaei_nima@yahoo.com</a></td>
<td>October 11-12</td>
</tr>
<tr>
<td>38. Cairo (Egypt)</td>
<td>Nermeen Galal <a href="mailto:nermeengalal@gmail.com">nermeengalal@gmail.com</a></td>
<td>October 18-19</td>
</tr>
<tr>
<td>39. Minsk (Belarus)</td>
<td>Michael Belevtsev <a href="mailto:belevtsev_m@mail.ru">belevtsev_m@mail.ru</a></td>
<td>October 22-23</td>
</tr>
<tr>
<td>40. Tirana (Albania)</td>
<td>Georgina Kuli-Lito <a href="mailto:gkuli_lito@hotmail.com">gkuli_lito@hotmail.com</a></td>
<td>November 19-20</td>
</tr>
</tbody>
</table>
J Project Meetings in East-Europe
2004-2008

1. Targu Mures, Romania, March 11-12, 2004; Organizer: Csilla Todea
2. Prague, Czech Republic, May 10-11, 2004; Organizer: Anna Sediva
3. Belgrade, Serbia/ Montenegro, June 11-12, 2004; Organizer: Srdjan Pasic
4. Skopje, Macedonia, September 17-18, 2004; Organizer: Katarina Stavrik
5. Kyiv, Ukraine, November 18-19, 2004; Organizer: Alla Volokha
6. Zakopane, Poland, December 16-17, 2004; Organizer: Ewa Bernatowska
7. Sofia, Bulgaria, April 15-16, 2005; Organizer: Elissaveta Naumova
8. Prague, Czech Republic, May 9-10, 2005; Organizer: Anna Sediva
9. Gdansk, Poland, September 23-24, 2005; Organizer: Ewa Bernatowska
10. Debrecen, Hungary, November 4-5, 2005; Organizer: László Maródi
11. Lviv, Ukraine, November 25, 2005; Organizer: Larysa Kostyuchenko
12. Oradea, Romania, December 20, 2005; Organizer: Zoltan Ellenes
13. Debrecen, Hungary, January 16, 2006; Organizer: László Maródi
14. Prague, Czech Republic, May 8-9, 2006; Organizer: Anna Sediva
15. Buchurest, Romania, June 9-10, 2006; Organizer: Nicolae Iagaru
16. Minsk, Belarus, November 9-10, 2006; Organizer: Michael Belevtsev
17. Debrecen, Hungary, December 8-9, 2006; Organizer: László Maródi
18. Zaporozhzhye, Ukraine, Apr 19-20, 2007; Organizer: Lyudmila Chernishova
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: Lyudmila Chernishova
24. Sunny Beach, Bulgaria, May 22-23, 2008; Organizer: Elissaveta Naumova
25. Sarajevo, Bosnia-Herzegovina, October 10-11, 2008; Organizer: Velma Mulaosmanovic
27. Riga, Latvia, November 27-28, 2008; Organizer: Tatjana Prokofjeva
# THE J PROJECT

## Steering Committee Members

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Genetic testing of PID genes in 2004-2008

**Primary immunodeficiency disorders**

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Genes available for genetic testing in the Debrecen Jeffrey Modell PID Reference Center

PRIMER IMMUNODEFICIENCIES (Genes)

1. X-linked agammaglobulinemia (BTK)
2. X-linked hyper-IgM syndrome (TNSF5=CD40L)
3. Activation induced citidine deaminase deficiency (AICDA)
4. Common variable immunodeficiency (TACI)
5. Common variable immunodeficiency (ICOS)
6. Hyper-IgD syndrome (MVK)
7. Hyper-IgE syndrome (STAT3)
8. X-linked severe combined immunodeficiency (IL-2RG)
9. IL7R deficiency (IL7R)
10. Rekombinase activator gene 1 deficiency (RAG1)
11. Rekombinase activator gene 2 deficiency (RAG2)
12. Familiar hemophagocitic lymphohistiocytic syndrome (PRF1)
13. X-linked lymphoproliferative syndrome (SH2D1A)
14. Autoimmune lymphoproliferative syndrome (FAS)
15. Autoimmune lymphoproliferative syndrome (FASLG)
16. Autoimmune polyendocrinopathy I syndrome (AIRE)
17. Dyskeratosis congenita (DKC1)
18. Cartilag-hair hypoplasia (RMRP)
19. Nijmegen-breakage syndrome (NBS1)
20. Shwachman-Diamond syndrome (SBDS)
21. Warts-Hypogammaglobulinemia-Infection-Myelokathexis syndrome /WHIM syndrome (CXCR4)
22. Wiskott-Aldrich syndrome (WAS)
23. Kostmann syndrome (HAX1)
24. Ciclic neutropenia (ELA2)
25. Severe congenital neutropenia (GFI1)
26. Severe congenital neutropenia (CSF3R)
27. X-linked chronic granulomatous disease (CYBB)
28. Autosomal recessive chronic granulomatous disease (NCF1=p47phox)
29. C2 deficiency (C2)
30. Hereditary angioedema (SERPING1)

LYSOSOMAL STORAGE DISORDERS (Genes)

31. Fabry disease (GLA)
32. Gaucher disease (GBA)
33. Niemann-Pick disease (SMPD1)

OTHERS (Genes)

34. Von Hippel-Lindau syndrome (VHL)
35. X-linked congenital adrenal hypoplasia (DAX1)
36. Galectin 3 deficiency (LGALS3)
AIM: To increase awareness on PID