



IPOPI EASTERN EUROPEAN REGIONAL MEETING
100th J Project Anniversary

Report on the IPOPI Eastern European Regional Meeting
15 March 2014, Antalya (Turkey)





I. Introduction

IPOPI Eastern European Regional Meeting took place on Saturday 15th March 2014 in Antalya (Turkey), following the 100th J Project Anniversary meeting. Representatives from 10 National Member Organisations gathered with physicians, industry representatives and IPOPI staff to explore the adaptation of the Antalya Consensus document to their national situation.

II. Presentations and discussions

- Introduction and presentation of the workshop – Jose Drabwell
- Introductory remarks – Dr. Wolfgang Knirsch
- NMO presentations:
 - IMYED main activities in Turkey – Selcan Kaya
 - Save Immunity main activities in Belarus– Dr. Svetlana Sharapova
 - Immunoprotect main achievements in Poland- Adrian Govecki
- Examples of advocacy and awareness campaigns – Jose Drabwell
- Working with and contributing to policy developments – Leire Solis
- NMO presentations – Chaired by Martine Pergent and Dragana Koruga
 - HOPI main achievements in Hungary – Zsuzsa Horvath
 - POPID activities and objectives in Bosnia and Herzegovina - Zlatko Adzovic
 - ARPID main activities in Romania – Artemiza Baldea
 - Imuno main activities in Slovenia – Maja Camernik
 - OSPID main achievements in Austria – Karin Modl
 - SUNFLOWER Organisation main activities in Russia - Anton Emelin
 - POsPID main achievements in Serbia – Dragana Koruga
- Discussion on the Eastern European patient priorities on the bases of the “Antalya declaration” – Chaired by Martine Pergent and Dragana Koruga





1. Introduction and presentation of the workshop – Jose Drabwell

Ms. Jose Drabwell, President of IPOPI, welcomed all the participants to the IPOPI Eastern European Regional Meeting. Ms. Drabwell explained the objectives of the meeting and invited the representatives of the National Member Organisations (NMOs) to share their experiences and objectives for the future with all the participants. By doing so, it would be easier to jointly discuss and agree on how to further implement the “Antalya declaration” in their respective countries.

2. Introductory remarks – Dr. Wolfgang Knirsch

Dr. Knirsch, VP International Business at Biotest, took the floor next to thank IPOPI for the organisation of such meeting and for all the attendants for participating in it. Dr. Knirsch expressed Biotest commitment to improve the diagnosis and treatment of patients suffering from Primary Immunodeficiencies (PIDs). By doing so, Dr. Knirsch highlighted the importance of patient involvement for attaining adequate and timely diagnosis and personalised treatment to the patient’s needs. As a closing remark, he expressed Biotest willingness to support patient and doctors activities.

3. NMO presentations - Chaired by Martine Pergent and Dragana Koruga

Ms. Selcan Kaya, President of IMYED, introduced the organisation’s activities to increase awareness of PIDs amongst the Turkish society and amongst the medical community, like the Bursa Immunology Symposium. Other activities carried out by IMYED aimed at supporting patients and their families, like World PI Week cultural activities.

Dr. Svetlana Sharapova, from Save immunity, provided the participants with an overview of the activities developed by the organisation and the PID medical community. In this sense, Dr. Sharapova explained that the first PID registry in Belarus was established in November 2006 and that currently, there are more than 200 patients with diagnosed PIDs. In terms of treatment, both IVIg and SCIg are available to patients, as well as bone marrow transplantation.



Mr. Adrian Govecki, President of Immunoprotect, highlighted the many achievements reached by the organisation. Amongst others, Mr. Govecki showed how the organisation worked and succeeded in making treatment for PIDs available for adult patients (as of 2015). Mr. Govecki also pointed out that a pilot project for newborn screening for Severe Combined Immunodeficiencies will be launch in 2015.

4. Examples of advocacy and awareness campaigns – Jose Drabwell

Ms. Drabwell provided participants with examples of the awareness campaigns success stories developed at international, European and national level. The presentation showed different examples that could be used as models by the NMOs and adapted to the specific objectives of the campaign and the audience targeted. Examples were shown of the IPOPI session for advocacy and media training in Eastern Europe in 2012, World PI Week NMO support programme, and IPOPI NMO PID Awareness Campaign Workshops (i.e. in Ireland, Romania, Spain or Brazil).



5. Working with and contributing to policy developments – Leire Solis

Ms. Leire Solis, Health Policy and Advocacy Manager at IPOPI, made a presentation how to contribute to policy developments at national level. In that sense, the presentation aimed at providing examples that would help participants to identify which of the objectives of the “Antalya declaration” would be a priority for the different NMOs present and help preparing the next steps for advocacy. Ms. Solis showed that the strategy behind an awareness campaign should be very much tailored to the specific situation of the country, in terms of the political agenda as well as the needs of the patients. Ms. Solis also highlighted the importance of combining efforts with other stakeholders in the field (rare plasma disorders patient groups, healthcare professionals or rare disease organisations).

6. NMO presentations - Chaired by Martine Pergent and Dragana Koruga



Ms. Zsuzsa Horvath, Vice-President of HOPI, provided an overview of the history of the organisation as well as of the challenges lying ahead. In that sense, Ms. Horvath identified the lack of education of PIDs amongst healthcare professionals as one of the major tasks that remained to be done for HOPI. Amongst the main achievements of the Hungarian NMO, Ms. Horvath highlighted the agreement reached with the Hungarian National Health Insurance with regards to the provision of individualised financing for PID patients, allowing them to receive the dosage required.

Mr. Zlatko Adzovic, Member of POPID, explained the main challenges of the new organisation in Bosnia and Herzegovina, amongst which: the lack of data on patient numbers or on diagnosed patients throughout the country, lack of understanding about PIDs amongst the medical community and society in general. From this perspective, Mr. Adzovic considered that hearing the experiences from other NMOs was very beneficial to get ideas for future activities in Bosnia and Herzegovina.

Dr. Artemiza Baldea, President of ARPID, gave an overview of the activities of the Romanian NMO, explaining the increase in number of members, as well as in the number of activities aimed at raising awareness amongst society. In this area, Dr. Baldea highlighted the activities developed for the previous campaigns of the World PI Week (26-29 April). Dr. Baldea also referred to the challenges lying ahead, including: Ig to be available to all patients, gaining access to obtain other medicinal products (subcutaneous immunoglobuline, antifungal drugs, etc) and continue collaborating with physicians and healthcare professionals.

Ms. Maja Camernik, member of the Slovenian Society for immune disorders, provided a detailed description of the situation of PID patients in Slovenia. Ms. Camernik explained the activities developed by the organisation to increase awareness amongst healthcare professionals and civil society. In Slovenia currently, there is no transition from children to adult care for PID patients and this was highlighted as one of the main challenges to work on in the next future.

Ms. Karin Modl, President of OSPID, presented some success stories developed by the Austrian association for PIDs. As she explained, the association managed to ensure that PID patients could obtain subcutaneous immunoglobuline throughout the country. She also referred to the invitation received by OSPID to have a representative in the expert panel for the development of the rare disease national plan.



Mr. Anton Emelin, from SUNFLOWER organisation, gave an overview of the achievements of the organisation since it was created 7 years ago. Amongst the main challenges that PID patients are confronted with, Mr. Emelin highlighted the access to diagnosis and to treatment for many patients. In the Russian national plan for rare diseases, only one PID was included, the rest of PIDs not being recognised as life-threatening and rare diseases, which prevents patients having their treatment reimbursed.

Ms. Dragana Koruga, President of POsPID, explained the participants the three main types of activities developed by the Serbian organisation: 1) supporting improvements in diagnosis and treatment (including contacts with the ministry of health); 2) awareness raising on PID among medical society, general population and patients; 3) supporting patients and families in coping with PIDs (summer camps).



7. Discussion on the Eastern European patient priorities on the basis of the “Antalya declaration”

The presentation provided by the representatives of the national organisations already pointed to some of the priorities in the different countries. In that sense, representatives highlighted the challenges patients with PIDs are currently facing to ensure that they get a timely diagnosis, a personalised treatment and adequate care for their disease, as well as the need for an improved PID knowledge amongst doctors and specialists, such as paediatricians, GPs, or lung specialists. In this part of the meeting, patients expressed the importance of meeting with patients from the region, so as to share and learn from their experiences on the basis of similar health and educational systems and transition processes. Overall, patients highlighted the importance of regional meetings to improve their strategic planning and coordinating efforts to increase the knowledge about PIDs and ensure adequate diagnosis, treatment and care for patients with these diseases.

Patient representatives from the different NMOs discussed the 5 priorities identified by experts and healthcare professionals in the “Antalya declaration” on the basis of the situation of PID patients in the different countries. As such, a prioritisation of the 5 targets of the “Antalya Declaration” was discussed and identified for each of the NMOs, following the table included below.

In terms of next steps, NMOs agreed translate the Antalya Declaration into their national language and to prepare and send a letter to their Ministries of Health to explain the main priorities for the national patient organisation, including and the “Antalya declaration”.

III. Priorities for Eastern countries on the basis of the “Antalya declaration”

Country	1 st priority	2 nd priority	3 rd priority	4 th priority	5 th priority
Austria	Education – increase education of doctors	Genetic diagnostic	Personalised Ig replacement treatment and HST		
Bosnia and Herzegovina	Proper education – lung specialists, paediatrics, GPs, accident and emergency specialists – raise awareness amongst them	Ig available to all patients in a long term basis and not to be requested on an annual basis			
Romania	Education – continuing medical education for physicians in primary care and hospitals	PID register -	Personalised Ig replacement – not to be based on a budget, but on the patients’ needs. Access to sub-cutaneous treatment		
Russia	Personalised Ig treatment and stem cell transplantation ... through education, public awareness, PID genetic diagnostic and a PID register				
Serbia	Education – support specialisation for immunologist paediatricians	Public awareness	PID genetic diagnostic and it should be provided through adequate reimbursement under request from doctor	PID register	Regular Ig replacement treatment
Slovenia	Education – bring immunology to be better explained to specialists; include nurses in the training	Public awareness to be raised.			



Participants list

Anton EMELIN,	SUNFLOWER Organisation (Russia)
Violetta KOZHEREVA,	SUNFLOWER Organisation (Russia)
Adrian GORECKI,	Immunoprotect (Poland)
Artemiza BALDEA,	ARPID (Romania)
Zsuzsa HORVATH,	HOPI (Hungary)
Karin MODL,	OSPID (Austria)
Christoph HABERL,	OSPID (Austria)
Maja CAMERNIK,	Imuno (Slovenia)
Senada ADZOVIC,	POPID (Bosnia and Herzegovina)
Zlatko ADZOVIC,	POPID (Bosnia and Herzegovina)
Selcan KAYA,	IMYED (Turkey)
Snezana OBRADOVIC,	POsPID (Serbia)
Svetlana SHARAPOVA,	Save immunity (Belarus)
Goran RISTICH,	Mother and Child Health Care Institute of Serbia (Serbia)
Nahla ERWA,	University of Khartoum (Sudan)
Roya SHERKAT,	Isfahan University of Medical Sciences (Iran)
Dorothea GROSSE-KREUL,	INGID
Amena WARNER,	INGID
Wolfgang KNIRSCH,	Biotest
Liye MAEY AMA,	Biotest
Jose DRABWELL,	IPOPI
Martine PERGENT,	IPOPI
Dragana KORUGA,	IPOPI
Leire SOLIS,	IPOPI