

Summary and action points

I. Introduction

On Saturday 17 November 2012, a workshop was organised by IPOPI, AEDIP (the Spanish Association of Patients with PIDs) and key Spanish medical stakeholders in order to provide AEDIP with:

- Concrete examples of successful awareness campaigns
- Overview of available IPOPI tools
- Overview of AEDIP main concerns at national level
- Overview of the European and Spanish environment in terms of legislation and patient advocacy
- Establish an awareness campaign plan



II. Presentations/Discussions

1. Presentation of IPOPI Awareness Campaign Toolkit – Magda Lourenço, IPOPI, and Leire Solís, Rohde Public Policy
2. Presentation of Awareness Campaign Success Stories – Teresa Español, IPOPI Medical Advisory Panel
3. Spanish political environment and rare diseases - Prof. José Luis Valverde, University of Granada
4. Opportunities for awareness raising campaigns at political level: EU and Spanish level – Sebastian Rohde and Leire Solís, Rohde Public Policy
5. Spanish patients and stakeholder perspective overview – Teresa Español, IPOPI Medical Advisory Panel
6. Spanish patient perspective – Petra Molinero, AEDIP
7. AEDIP 2013 communication strategy and envisaged activities – Pep Llopis Cascales, AEDIP

1. Presentation of IPOPI Awareness Campaign Toolkit

Magda Lourenço, IPOPI Executive Assistant, presented the different IPOPI support programmes and toolkits to support National Member Organisations (NMOs) in developing their activities at national level. Ms. Lourenço presented the following toolkits and guideline documents:

<ul style="list-style-type: none">• Broadcast Guidelines;• Facts about PID for Governments• Media Guidelines• Guidelines on Corporate Sponsorship• Government Outreach Guidelines	<ul style="list-style-type: none">• Celebrity Guidelines• Family & School Guidelines• PID Leaflet IPOPI• Facts about PID for the Medical Profession
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2. Presentation of Awareness Campaign Success Stories

Dr. Teresa Español, President of IPOPI's Medical Advisory Panel, went over examples of successful awareness campaigns that have been developed at international level and in different countries. The presentation from Dr. Español 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.

Dr. Español provided specific examples on the patient awareness campaign workshops that took place in Belgium and Ireland, as well as on an IPOPI Professionalization workshop held in Russia. Dr. Español also reported on the World Primary Immunodeficiency Week to outline an example of a successful international and multi-stakeholder campaign which IPOPI is supporting and which IPOPI's NMOs have been implementing at the national level.

3. Spanish political environment and rare diseases

Prof. José Luis Valverde, from the University of Granada, provided an overview of the health system organisation in Spain and the legislation developed in the area of rare diseases. Prof. Valverde outlined how Spanish public health competences are organised, between the Spanish Ministry of Health and the health departments of the autonomous regions.

Once this general overview was provided, Prof. Valverde focused on the specificities of the activities developed for the protection and support of patients with rare diseases. In this sense, the current legislation and policy in Spain is articulated around several initiatives: the National Strategy for



Rare Diseases (2009), the Royal Decree-Law on Centres, Services and Reference Units, and the different regional plans in the area of rare diseases or the Spanish Government Working Document 2011-2012 for the treatment of rare diseases. Given the current context of the economic crisis, Prof. Valverde referred to the cost-containment policies developed by the national government as well as the situation that the regions are facing in terms of budget restrictions.

4. Opportunities for awareness raising campaigns at political level: EU and Spanish level

Sebastian Rohde and Leire Solís, consultants from Rohde Public Policy, provided participants with an overview of the political opportunities for awareness-raising and advocacy campaigns. The presentation aimed at providing participants with an analysis of the upcoming opportunities at political level that could be used to increase awareness about PID and the key issues that PID patients are facing in Spain. One of the main opportunities identified was the decision by the Council of Ministers on 26 October 2012, to make 2013 the Spanish Year for Rare Diseases. 2013 will most probably see a review of the National Strategy on Rare Diseases, launched in 2011, which could be used as a hook by AEDIP to get active and increase political awareness of PID at national and regional level.

5. Spanish patients and stakeholder perspective overview

Dr. Teresa Español gave a presentation on PID patients' needs from a medical perspective. Dr. Español approached the situation patients were facing from the following perspectives:



- Lack of knowledge and awareness about PIDs in the medical community, especially among haematologists, pneumologists or adult gastroenterologists. In the medical community awareness amongst paediatricians is higher as they have to confront very severe cases of PIDs.
- Need for early diagnosis: in many cases, the diagnosis of a patient with a certain type of PID is not achieved due to the lack of awareness among the specialist medical community and the lack of information about the diseases as such.
- Lack of awareness about treatment: Centres of Reference are the best settings for patients to receive adequate treatment by specialists.
- Recognition of disability status: PIDs are currently not on the list of chronic diseases consequently prophylactic antibiotics are not covered as part of PID treatment. Other diseases such as CF are included as a chronic disease so this could be viewed as discrimination for PIDs.
- Treatment access: in Spain treatments provided to patients at hospital level are covered by the Spanish Social Security and patients do not need to pay for them. The access to antibiotics which is an essential part of the treatment has to be paid for by the patient.

- Increased awareness about the existence of a national and regional patient association: Lack of contact between AEDIP and the Spanish immunologists, no recommendations from doctors for patients to join AEDIP.

6. Spanish patient perspective

Petra Molinero, speaking on behalf of AEDIP's President, José González Hierro, informed participants about the main problems and objectives identified as essential by AEDIP.

- Ensure the appropriate provision of Immunoglobulin (IG) therapies in hospitals
- Hospitals treating PID patients should ensure the availability of, at least, two different types of products, in view of the adverse reactions that can occur amongst patients using these therapies.
- Increase awareness of PID among the medical community, as well as among health authorities, so as to ensure timely diagnosis and treatment and the recognition of clinical immunology as a discipline of its own.
- Access to treatment outside the region of residence and when travelling in the EU: the treatment levels differences within Spain, due to different regional policies were highlighted as well as those encountered to access appropriate treatment when travelling within the EU.
- Inclusion of PIDs in the list of chronic conditions list in Spain: this would facilitate the granting of the disability status to patients suffering from severe cases of PIDs by medical juries in charge of examining disability claims, but also ensure free access to antibiotics.
- Involvement of immunologists in the patient organisations
- Provision of information to women carriers of PIDs in case of pregnancy (genetic counselling, abortion, etc)

7. AEDIP 2013 communication strategy and envisaged activities

Pep Llopis presented the 2013 communication strategy of the Association. The strategy is based on the following 4 points:

- Awareness raising campaigns based on paper-support tools (posters for hospitals, flyers, etc).
- Further development of AEDIP's website and social networks so as to increase dialogue with patients and potential members of the Association.
- Organisation of social activities with the objective of reaching more patients, patient families and the society in general.
- Enhance dialogue with authorities, so as to ensure patients' rights.

Las **idp** son defectos de la respuesta inmunológica producidos por errores congénitos y a menudo hereditarios, de algunos de los mecanismos necesarios para, entre otras funciones, responder a las agresiones de los agentes infecciosos.

¿idp?

Las infecciones repetidas han de hacer sospechar de algún defecto inmunológico.

El diagnóstico precoz de una **idp** es esencial para iniciar el tratamiento y conseguir buenos resultados.

Con unas **análisis sencillos** se pueden hacer **buenos diagnósticos**.

Las **idp** se pueden diagnosticar y **¡tratar!**

AEDIP
Asociación Española de Defectos Inmunológicos Primarios

IPOPI

8. Local strategy – the way forward: agreements on potential actions and timelines

Throughout the different sessions, participants expressed their views on what could be AEDIP strategic objectives and the support needed from IPOPI.

The participants agreed on the following items:

Inclusion of PIDs in the list of chronic conditions list:

- Dr. Español explained how the diseases included in the list of chronic conditions, such as cystic fibrosis, had their treatment covered by the national Security System, including the antibiotics.
- The inclusion of PIDs in such list would also facilitate the recognition by the medical juries of the debilitating effect of PIDs and facilitate obtaining the recognition of disability.



Increase awareness of PIDs among the medical professionals:

- Participants agree that one of the main problems for a timely diagnosis and care is the lack of awareness among healthcare professionals about PIDs.
- AEDIP members in the different regions agreed to establish and/or further develop their links with medical professionals with the objective to increase awareness and potentially suggest their involvement in AEDIP's activities.

Development of consensus document on principles of care for PIDs in Spain:

- The members of AEDIP considered that the development of a consensus document that would provide guidance and recommendations for the provision of care in Spain. This document would then be used to increase awareness amongst professionals, facilitate discussions with regional and national policymakers and further develop social awareness on PIDs.
- It was suggested that the document could have a representation of specialists and policymakers from regional, national and European level so as to widen the base of supporters and ensure a full representation of key-decision makers.

Participants agreed on the following objectives:

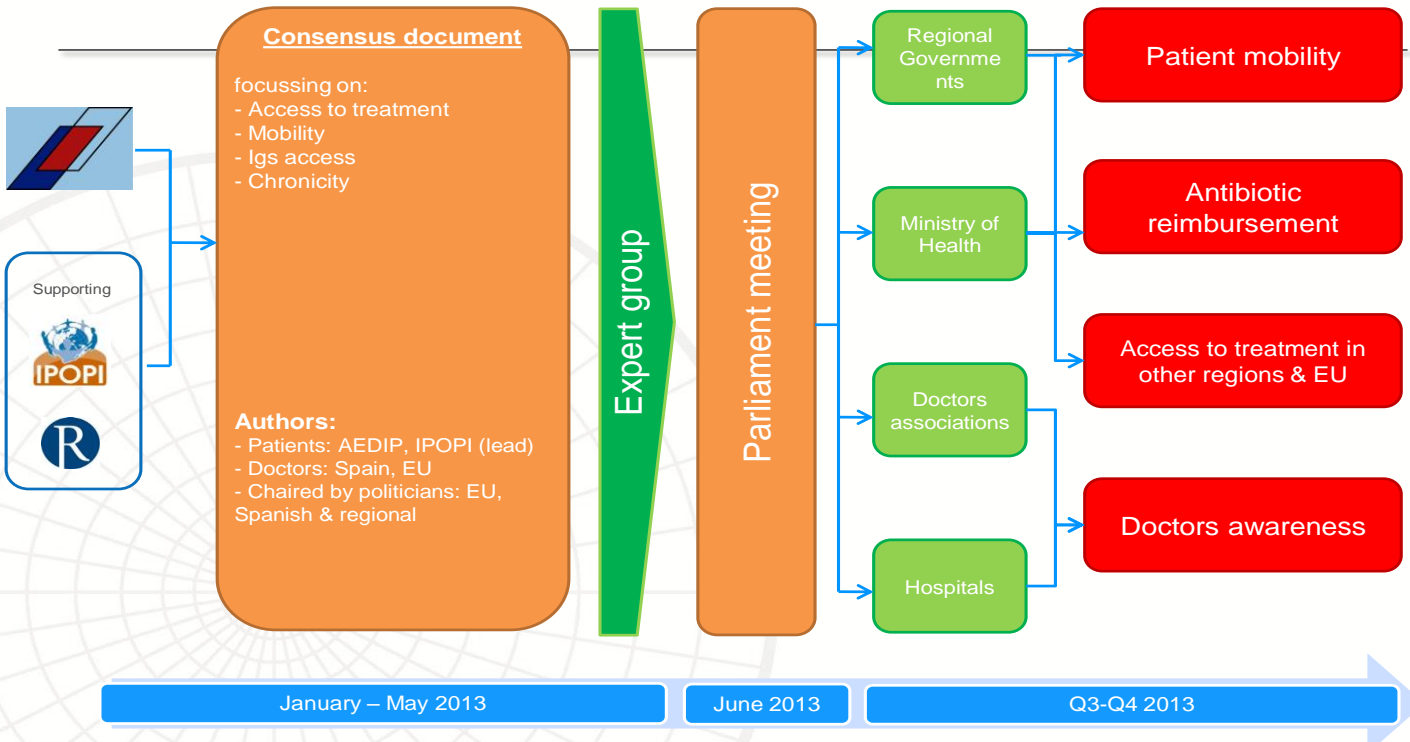
Direct/Practical patient care issues	Structural care issues
<ul style="list-style-type: none"> • Antibiotics to be reimbursed through the national security system • At least two types of IGs in hospitals treating PID patients • Awareness of medical community about PID • Increase public awareness about PID 	<ul style="list-style-type: none"> • PIDs in the list of chronic diseases • Access to treatment outside of the region of residence

Participants agreed that a letter of support from IPOPI to AEDIP would be needed. Additionally, it was considered necessary to elaborate a consensus document that would incorporate recommendations at national level for tackling the identified issues that patients with PIDs are facing in Spain.

The following list of activities and timing was identified:

Activity	Timing	Responsibility
<p>Political awareness campaign:</p> <ul style="list-style-type: none"> • Continuation of contacts with regional authorities in Cataluña and Andalucía • Development of contacts with other regional authorities, i.e. Madrid, Mallorca or Valencia. • Drafting of support letter to be used in contacts with regional/national policymakers 	<p>Q4 2012 – Q1 2013</p> <p>Q4 2012 – 2013</p> <p>Q4 2012</p>	<p>AEDIP</p> <p>AEDIP</p> <p>IPOPI</p>
<p>Awareness raising campaign among medical community:</p> <ul style="list-style-type: none"> • Increase contacts with specialists in hospitals providing treatment to PIDs patients 	<p>Q4 2012 - 2013</p>	<p>AEDIP</p>
<p>Awareness raising campaign among society:</p> <ul style="list-style-type: none"> • Further development of 2013 communication strategy • Participation in the World PID Week 	<p>Q4 2012 - 2013</p> <p>Q1 – April 2013</p>	<p>AEDIP with support from IPOPI</p>
<p>Development of a national consensus paper</p> <ul style="list-style-type: none"> • Creation of an expert group with experts, patients and policymakers at European, national and regional level. • Development of a consensus paper/national recommendations • Organisation of parliamentary event for the launch of the consensus paper/national recommendations 	<p>Q1 2013</p> <p>Q1-Q2 2013</p> <p>June 2013</p>	<p>IPOPI, AEDIP & RPP</p> <p>IPOPI & RPP</p> <p>IPOPI & RPP</p>

Drivers > Tools & Supporters > Targets > Objectives





IPOPI Awareness Raising Workshop 17 November 2012

III. List of participants

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Pep Llopis Cascales	AEDIP
Paquita Bernardino Infantes	AEDIP
Desiree Juan Aguado	AEDIP
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Carlos Jimenez Contreras	AEDIP
José-Luís Valverde	University of Granada
Teresa Español	IPOPI Medical Advisory Panel
Jose Drabwell	IPOPI Chairperson
Magda Lourenço	IPOPI Executive Assistant
Sebastian Rohde	Rohde Public Policy
Leire Solís	Rohde Public Policy