IPOPI Awareness Raising Workshop
Gresham Hotel, Dublin, Ireland
12 May 2012
Summary and Action Points

I. Introduction

On Saturday 12 May 2012, a workshop was organised by IPOPI with PID patients and scientists in order to provide patients with:

- concrete examples of successful awareness campaigns
- overview of available IPOPI tools
- overview of the Irish environment in terms of patient awareness and advocacy from a key patient advocate with a wealth of experience in leading successful patient groups in Ireland
- Establish a stepwise awareness campaign plan

II. Presentations/Discussion

1. Presentation of IPOPI Awareness Campaign Toolkit, Johan Prevot, IPOPI
2. Presentation of Awareness Campaign Success Stories, Jose Drabwell, IPOPI
3. Irish Patients & Stakeholder Perspectives Overview, Dr Mary Keogan
4. Opportunities for awareness raising campaigns at political level: EU and Irish level, Sebastian Rohde, Rohde Public Policy
5. Irish Patient Campaign success stories, Larry Warren, PLUS Steering Committee / ex-CEO Alpha 1 Ireland Patient Organisation
6. Local strategy – the way forward : Agreements on potential actions and timelines

1. Presentation of IPOPI Awareness Campaign Toolkit

Johan Prevot, IPOPI Executive Director, presented the Awareness Campaign Toolkit prepared by IPOPI to support National Member Organisations (NMOs) in their national activities. Mr. Prevot explained the difference objectives targeted by the Toolkits:

- Increasing diagnosis and care
- Increasing the visibility and raise awareness about PID
- Position and support the activities NMOs
- Foster internal governance within the NMOs

Mr. Prevot introduced the different tools provided by IPOPI to NMOs:

• Broadcast Guidelines; • Facts about PID for Governments • Media Guidelines • Guidelines on Corporate Sponsorship • Government Outreach Guidelines	• Celebrity Guidelines • Family & School Guidelines • PID Leaflet IPOPI • Facts about PID for the Medical Profession

2. Presentation of Awareness Campaign Success Stories

Jose Drabwell, Chair of the Executive Committee of IPOPI, provided the participants with several examples of awareness raising campaign and explained the different approaches taken by the different NMOs. Ms. Drabwell started by explaining the little awareness about PID among GPs, the medical community and society in general.

The presentation gave an overview of the different IPOPI and NMOs campaigns at European and International level. The examples of the campaign in Russia, the Czech Republic, Sweden or the ones organised around the World PID Week clearly showed the various possibilities available for launching a campaign. In this sense, participants were shown how campaigns should be differently elaborated depending on the target audience and the many tools available.

3. Irish Patients & Stakeholder Perspectives Overview

Dr. Mary Keogan, Immunologist at the Beaumont hospital, presented the immunodefiency services in Ireland. In her presentation, Dr. Keogan addressed the current situation patients and immunologists are currently facing and provided ideas on how to tackle the system shortcomings.

Dr. Keogan explained how PID needed to get into the politicians' agenda in order to be prioritised. In Ireland, there are several problems regarding the provision of treatment for PID:

1. Funding for PID treatment is a problem as given that:
    - The funds are not allocated per number of patients;
    - There is no incentive for hospitals to increase their capacity and, in reality, the incentives seek not to increase the infusion capacity;
    - Shared care is becoming very difficult;
    - Home therapy funding is very variable and difficult to obtain in a long-term basis;
    - The funding situation is likely to deteriorate.

Dr. Keogan explained how, in this situation, a strong patient voice is the only way to get PID back on the agenda.

2. There is a lack of expertise in the delivery of treatment:
    - Psychology access is only possible through psychiatry;
    - Access to medication is no longer automatically funded (as it is the case, for instance, for the Icatibantin community);
    - There are and have been national changes in pharmaeconomic assessment that have resulted in reducing the amount per Qualy funded;
    - Some drugs that were previously funded have been withdrawn;
    - Some patients that do not have the medical card are struggling.

For these reasons, the involvement of patients in campaigns to raise political awareness is essential: past examples show that this type of campaigns works (i.e. melanoma campaign).

3. In terms of awareness, diagnosis and treatment of PID:

- Late diagnosis is a major issue;
- GPs access to lab testing is being restricted;
- Scientists ability to access tests abroad will be restricted;
- Currently there are patients on immunoglobulin (including home therapy) following their treatment without the involvement of an immunologist;
- There is a lack of public and healthcare professional education on this topic;

Through patient power, PID could achieve several objectives, such as:

- Support: for the treatment at political level and raising awareness about the socio-economic benefits of healthy patients who can fully contribute to society
- Lobby for treatments: i.e. reduce the amount of paper work spent in requesting treatment, therefore reducing time spent with patients
- Awareness about the disease
- Medical card/cover: i.e. putting immunoglobulin in the long-term reimbursement list, which requires a change in the legislation.

4. Opportunities for awareness raising campaigns at political level

Sebastian Rohde, Consultant from Rohde Public Policy, provided the participants with an overview of the opportunities for awareness raising campaigns, from a political perspective. The aim of the presentation was to provide participants with some view of the upcoming opportunities in the political agenda that could be used to increase awareness about PID. In this sense, Mr. Rohde highlighted the change of perception regarding rare diseases that had happened in Ireland in the past year, with the debate organised in the Parliament Committee for Health and Children and rare diseases organisations (on 29 February 2012) and the Motion for action on rare diseases passed by the Senate (7 March 2012). In this context, Ireland is currently developing its national plan on rare diseases, which could be a good opportunity for raising political awareness on PID. With the upcoming Irish Presidency of the Council of the European Union (Council of Ministers of the Member States) from January to June 2013, Irish patients have a good chance to show cast Irish achievements in terms of rare diseases and promote them throughout the EU.

5. Irish Patient Campaign success stories

Larry Warren from PLUS, a European patient group for people who use plasma and protein products, provided the participants with good practices and recommendations for setting up a patient group. In this sense, he highlighted that a patient group would, not only inform the patients and their families, but in general end the isolation in which patients suffering from rare diseases live and help them taking control of their conditions and lives. Mr. Warren advised patients to use all the possibilities to gain visibility, such as attend all the meetings that they get invited to, use charity events to raise visibility for the organisation and join other umbrella or support groups (i.e. IPOPI, IPPOSI, MRCG or PLUS).

6. Local strategy – the way forward: Agreements on potential actions and timelines

Participants held discussions on the best steps forward throughout the meeting and based on the presentations provided. The participants agreed on the following items:

Change in the long-term illness card:

- Dr. Keogan, together with the participants, discussed the possibility in changing the situation of the long-term illness card. Larry explained that the diseases giving access to the long-term illness card are decided by the Health Service Executive (HSE).
- A good tactical approach towards the inclusion of PID within the list of conditions giving access to a long-term illness card would be to present the costs to the healthcare system that would be saved.

Urgency medication:

- Some of the conditions require an emergency kit, especially when the patient is travelling abroad. The situation in Ireland makes that patients do not have access to such kit, not even when travelling abroad where they are required to do so. Having access to the urgency medication would have a big and positive impact on the manageability of the disease, empower the patient and could even prevent deaths

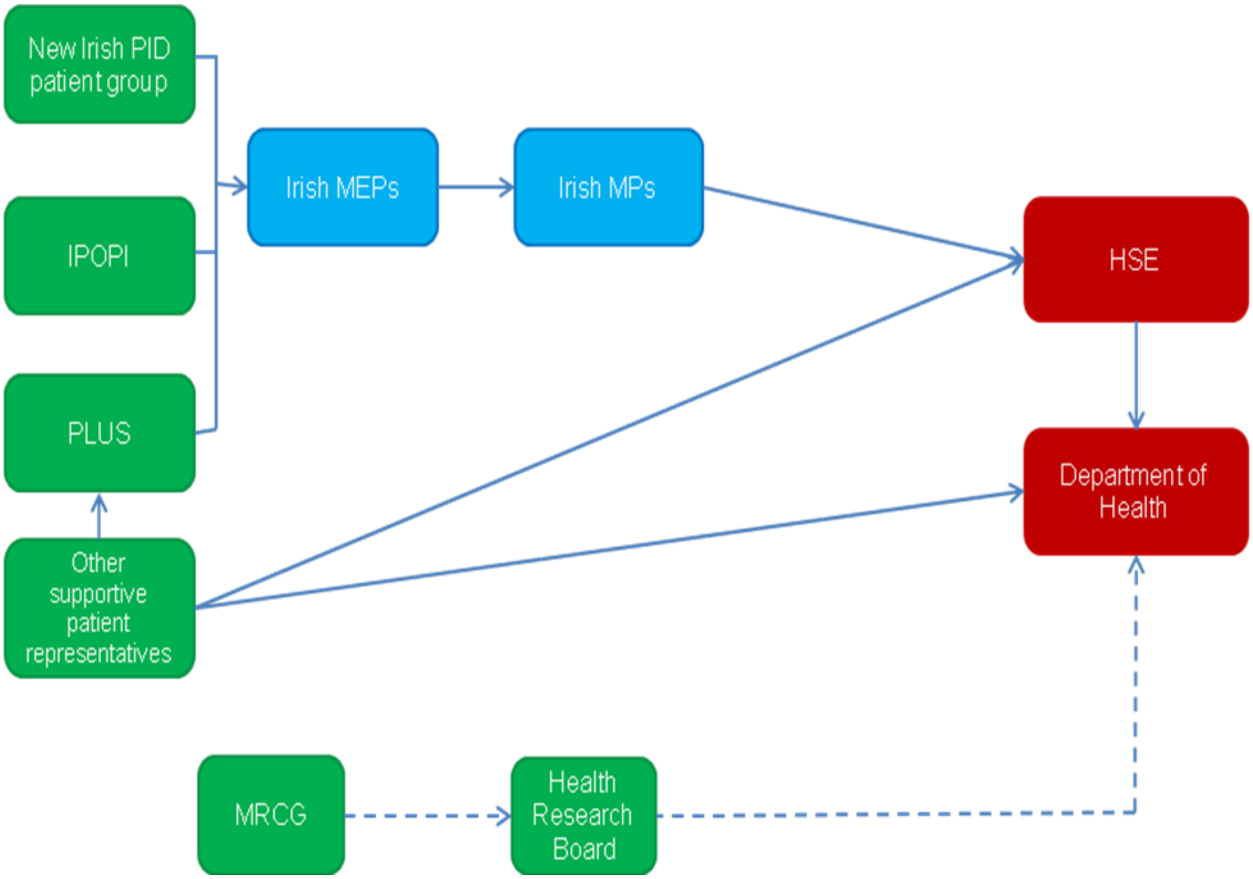
- It was also mentioned that Irish doctors are not aware of the current situation. In this sense, it would be necessary to raise awareness amongst them so they could help in tackling this situation.

The participants agreed on the following objectives:

Direct/Practical patient care issues	Structural care issues
• Emergency medication • Long-term illness card • Affordability of the medication	• Centres of reference • Funding to hospitals/treatment units

The participants agreed that the next steps should focus on two items under "direct/practical patient care issues": emergency medication and the long-term illness card.

The participants agreed on the following strategy:



Timeline and responsibilities:

Activity	Deadline	Responsibility
NMO set-up: • Circulation of the statutes from the previous organisation to all the participants • Selection of a location for the next NMO meeting • Support in the organisation of the next NMO meeting • Provision of a strategy and information on Irish groups that the NMO should consider in their future activities	23 June May-June May-June June-July	Maria Nolan All participants IPOPI RPP
Political awareness campaign: • Organisation of meetings with Irish MPs • Organisation of meetings with Irish MEPs • IPOPI PID Forum on Rare Diseases plans	Oct-Nov 26 Sep	NMO IPOPI & RPP
Awareness raising campaign: • Discuss the possibility of developing a programme for the World PID Week	June-April 2013	NMO with support from IPOPI

List of participants

Jose Drabwell	IPOPI
Johan Prevot	IPOPI
Larry Warren	PLUS Steering Committee / ex-CEO Alpha 1 Ireland Patient Organisation
Yvonne Rooney	Irish PID patient representative
Paul Rooney	Irish PID patient representative
Alison Coffey	Irish PID patient representative
James Nolan	Irish PID patient representative
Maria Nolan	Irish PID patient representative
Paul Rooney	Irish PID patient representative
Yvonne Rooney	Irish PID patient representative
Kathryn Gouldsbury	Irish PID patient representative
Martha Gouldsbury	Irish PID patient representative
Dr Mary Keogan	Beaumont Hospital
Dr Jimmy Gooi	Beaumont Hospital
Sebastian Rohde	Rohde Public Policy (Consultant)
Leire Solis	Rohde Public Policy (Consultant)