



Working with and contributing to policy developments

IPOPI Eastern European Regional Meeting
100th J Project Anniversary
Antalya, Turkey
15 March 2014

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- Thanks to all participants (patients & doctors) for joining the discussions today!
- Thanks to Biotest for supporting the organisation of this meeting!



We are stronger if we work together!

INTRODUCTION

- Objective: provide with examples that can be used to trigger ideas for future advocacy campaigns.
- Objective: facilitate the identification of goals and objectives tailored to national situation and help preparing the next steps.

IDEAL SCENARIO



- PID patients receiving access to early diagnosis, treatment & the associated care to match their needs, having them covered by the national/regional budget.
- PID patients being able to live a normal and productive life, without having to worry about their treatment & care.

WHY BECOMING ACTIVE AT POLITICAL LEVEL?

- Health policy is aimed at supporting patients, including those with PIDs.
- Policy makers do not know about Rare Diseases (RD) in general and PIDs in particular.
- Society needs greater awareness about PIDs.

Policy makers are the ones adopting policy and legislation and the budget to implement them!

KEYS FOR A SUCCESSFUL CAMPAIGN

- A successful campaign results in a win-win situation for campaigners and politicians;
- Need to link campaign's objectives with policy makers' agendas;
- Activities to be developed depend on the topic and political environment:
 - The topic is on policy makers' agenda already;
 - The topic is known and out of the political agenda;
 - The topic is unknown and out of the political agenda.

TOPIC ON POLICY MAKERS' AGENDA

– IRELAND - (1)

- **What?** Launch and implementation of a Rare Disease (RD) Plan in Ireland.
- **Why?** RD Plan discussed but delayed in its adoption (beyond EU deadline) & PID patients not being consulted in the development.
- **How?**
 - By contributing to the consultation of the Government;
 - By following-up on the delay with Irish Members of the European Parliament (MEPs).

TOPIC ON POLICY MAKERS' AGENDA – IRELAND - (2)

- **Who?** IPIA (Irish group) in contact with Irish policy makers through Irish MEPs
- **Results?** Parliamentary Question addressed by an Irish MP to Irish Minister of Health. Follow-up will soon take place!

TOPIC ON KNOWN BUT NOT IN THE POLITICAL AGENDA – SPAIN – (1)

- **What?** Facilitate receiving diagnosis and treatment in a different Spanish region.
- **Why?**
 - Regionalised health services do not favour cross-region diagnosis & treatment.
 - At EU level, favouring cross-border healthcare.

TOPIC ON KNOWN BUT NOT IN THE POLITICAL AGENDA – SPAIN – (2)

- **How?**
 - By meeting Minister of Health to provide concrete examples of the situation facing PID patients;
 - By providing tools to develop the requested protocols;
 - By requesting a letter of support from IPOPI.
- **Who?** AEDIP (Spanish group) with punctual support of IPOPI.
- **Results?** On-going discussions with the MoH. Ideally, the protocol should be discussed by MoH and representatives of the regions for adoption.

TOPIC UNKNOWN AND OUT OF THE POLITICAL AGENDA – FRANCE – (1)

- **What?** Parliamentary event & adoption of Recommendations in France.
- **Why?** To provide a political support to PIDs and leverage on the work done at EU level.
- **How?**
 - By engaging with policy makers to create political awareness;
 - By adapting EU Recommendations to the French situation;
 - By ensuring an adequate follow-up.

TOPIC UNKNOWN AND OUT OF THE POLITICAL AGENDA – FRANCE – (2)



- **Who?** IRIS (French group) and IPOPI in collaboration with policy-makers.
- **Results?**
 - IRIS being consulted by an MP on the topic of blood and blood products.
 - Increased awareness on PIDs amongst policy makers.
 - IRIS has a set agenda to be developed at political level.

WORKING WITH OTHER STAKEHOLDERS



By working with other groups that share same interests, we are stronger!

- Doctors (LASID, ASID, ASIA,...)
- Nurses
- Stakeholder platforms
 - Eurordis;
 - Epposi;
 - IAPO, etc.

WORKING WITH OTHER STAKEHOLDERS



- PLUS:
 - the consortium representing patients affected by rare plasma disorders (i.e. haemophilia, Alpha 1 anti-trypsin).
 - Activities: EU Call for Action on Rare Plasma Disorders.
- Haemophilia groups
- Industry
- Policy makers & Regulators

Thank you!

