IPOPI XIIth Biennial Meeting
NMO Advocacy and Media Workshop

Successful Advocacy and Lobbying – some examples of how it is done!

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IPOPI

Thursday 4 October 2012
Hall E, Firenze Fiera, Fortezza da Basso
Florence, Italy

20th Anniversary IPOPI

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1. WHO Essential List of Medicines campaign
2. HIV and Haemophilia campaign

1. WHO EML

- World Health Organization (WHO) is the United Nations specialized agency for health.
- Established on 7 April 1948
- WHO's objective, as set out in its Constitution, is the attainment by all peoples of the highest possible level of health.
- WHO is governed by 193 Member States through the World Health Assembly.
  - Composed of representatives from WHO's Member States. The main tasks of the World Health Assembly are to approve the WHO programme and the budget for the following biennium and to decide major policy questions.
- Main impact and effectiveness in developing world

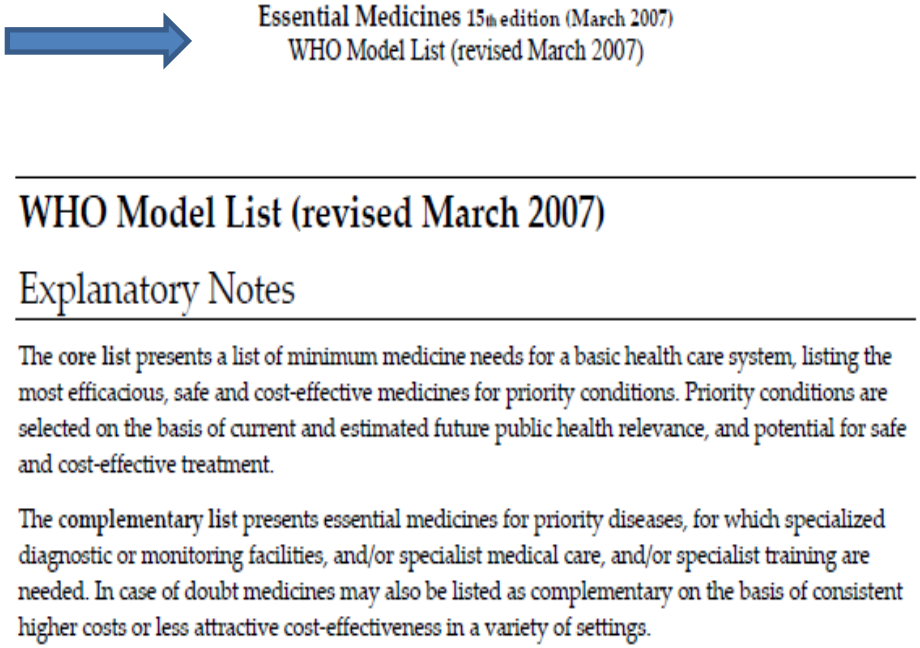
1. WHO EML

- WHO's vision is that people everywhere have access to the essential medicines they need and:
  - that the medicines are safe
  - Effective
  - Of good quality
  - and that the medicines are prescribed and used rationally.
- Essential medicines are those "that satisfy the priority health care needs of the population".

1. WHO EML

- In order to provide guidance on which medicines are ‘essential’…

Essential Medicines 15th edition (March 2007)
WHO Model List (revised March 2007)



WHO Model List (revised March 2007)

Explanatory Notes

The core list presents a list of minimum medicine needs for a basic health care system, listing the most efficacious, safe and cost-effective medicines for priority conditions. Priority conditions are selected on the basis of current and estimated future public health relevance, and potential for safe and cost-effective treatment.

The complementary list presents essential medicines for priority diseases, for which specialized diagnostic or monitoring facilities, and/or specialist medical care, and/or specialist training are needed. In case of doubt medicines may also be listed as complementary on the basis of consistent higher costs or less attractive cost-effectiveness in a variety of settings.

Essential Medicines Committee

- Drawn up by the WHO Expert Committee on the Use of Essential Drugs
- Committee convenes every two years to update the list
- Comprises 8 to 12 members drawn from the WHO Expert Advisory Panels for Drug Evaluation and for Drug Policies and Management and other expert advisory panels
- Coordination of submissions for inclusion in the list by Secretary of the Expert Committee

1. WHO EML

A little bit of history….

- Historically list included Polyvalent Human Immunoglobulins (IG's) and Clotting Factors

Up to 12th List:

19. IMMUNOLOGICALS		
19.1 Diagnostic agents		
All tuberculins should comply with the WHO Requirements for Tuberculins (Revised 1985). WHO Expert Committee on Biological Standardization Thirty-sixth report, (WHO Technical Report Series, No. 745, 1987, Annex 1).		
tuberculin, purified protein derivative (PPD)		injection
19.2 Sera and immunoglobulins		
All plasma fractions should comply with the WHO Requirements for the Collection, Processing and Quality Control of Blood, Blood Components and Plasma Derivatives (Revised 1992). WHO Expert Committee on Biological Standardization Forty-third report, (WHO Technical Report Series, No. 840, 1994, Annex 2).		
anti-D immunoglobulin (human)		injection, 250 micrograms in single-dose vial
□ antitetanus immunoglobulin (human)		injection, 500 IU in vial
antivenom serum		injection
diphtheria antitoxin		injection, 10 000 IU, 20 000 IU in vial
immunoglobulin, human normal	(2)	injection (intramuscular)
immunoglobulin, human normal	(2, 8)	injection (intravenous)
□ rabies immunoglobulin		injection, 150 IU/ml in vial
19.3 Vaccines		

1. WHO EML

- In 2003, decision to remove IG from EML and continuation of clotting factors on the list to be reviewed.

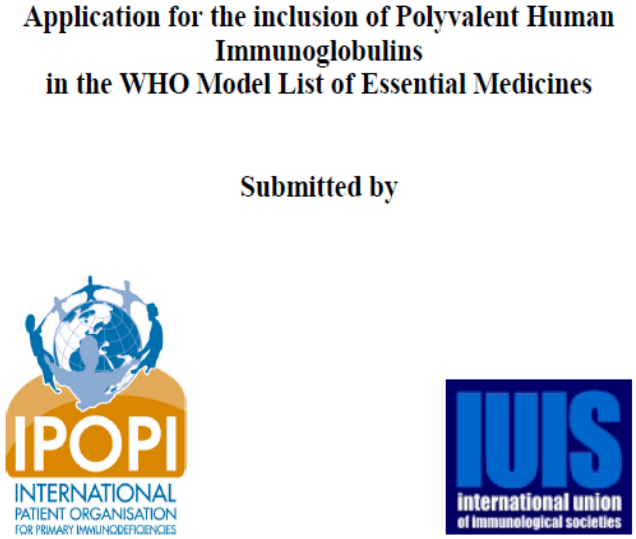
- WHO Reasons for removing IG were not rational:
  - no need for IG's in view of the availability of suitable vaccines
  - no WHO clinical guidelines recommending its use

1. WHO EML

- The decision to remove IG's on these grounds led several organisations including IPOPI, IUIS and PPTA to request its reinstatement in the list in 2005, **BUT** individually:
- WHO 2005 decision:
  - While Clotting factors maintained on list
  - Rejection of attempt to get IG's reinstated
- WHO Reason for rejecting reinstatement:
  - Prevalence of target diseases is very rare
  - Insufficient evidence of its efficacy
  - Cost effectiveness
- Stakeholders failed to advocate successfully

1. WHO EML

- In 2006, stakeholders decided to re-launch an advocacy campaign but this time working TOGETHER


Application for the inclusion of Polyvalent Human Immunoglobulins
in the WHO Model List of Essential Medicines

Submitted by

IPOPI INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES

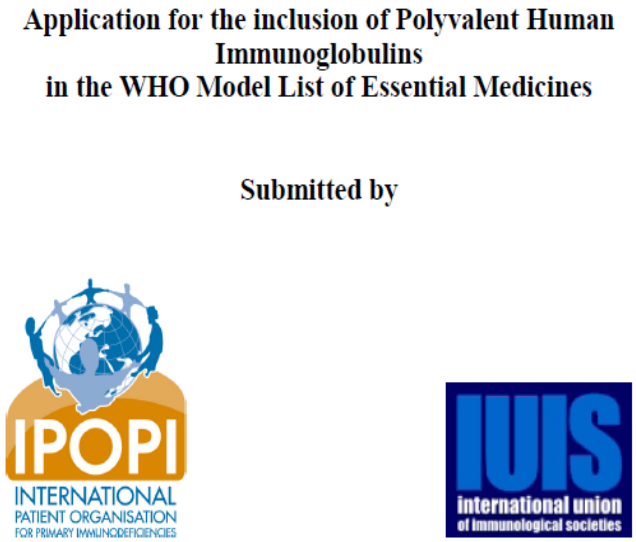
IUIS international union of immunological societies

Stakeholders included:

- IPOPI & its NMOs
- IUIS, ESID, INGID and national societies
- Other PLUS patient groups and their NMOs
- Industry associations
- WHO Global Collaboration for Blood Safety
- International experts call to action – around 50 signatures!

1. WHO EML

- Other key factors :



- Dossier was prepared in respect of the bureaucratic requirements of WHO:
  - Timelines
  - Format
  - Submission to appropriate committee/correct target
  - Supported by Data
  - Supported by Call to Action
  - Supported by presentation at committee meeting in 2006

1. WHO EML

- WHO 2007 decision:
  - Resintatement of immunoglobulins
  - PID listed as top two priority Indications
  - Subcutaneous since then added following IPOPI & IUIS request
- The Lesson:
  - Identify the issue
  - Identify what needs to be done – from your perspective and form the institution you will advocate to
  - Identify who are your supporting stakeholders
  - Collect Data
  - Call to Action – get as much support as you can
  - Respect timelines & format
  - WORK TOGETHER & REQUEST A MEETING TO MAKE YOUR CASE!
  - Ensure contacts have been secured & follow up !

2. HIV & Haemophilia

- A major medical catastrophe infected large numbers of people with haemophilia with HIV in the early 1980s.
- This resulted in serious illness, inability to work or attend education and early death.
- Poor prognosis for those infected – no treatments then – limited knowledge.
- Clearly many people were to face early death and profound hardship.

2. HIV & Haemophilia

- The UK Haemophilia Society saw this as a major concern and formulated an advocacy campaign to compensate for the loss.
- Important not to make enemies – detracts from the main issue. Know your friends!
- We knew our way around our Ministry of Health – personal friend of Health Minister's wife!
- The media played an important role but had to be controlled!

2. HIV & Haemophilia

- In the early 80s data collection was poor – no one knew how many had been infected.
- Important to know your community – we had a guesstimate the numbers involved – **DO NOT DO THAT NOW!! Be prepared!!**
- The campaign ran through Parliament, radio, television, newspapers and magazines. You must have patients who are prepared to 'go public' – ***special preparation needed.***
- ***Know who to use from your team!***

2. HIV & Haemophilia

- In 1983 we honestly thought that all infected pwh would die – many are still alive and leading productive lives. However, the campaign gained strength from that thought – balance public statements!
- At the end of the day something like £100m was obtained from the UK Government and a Trust established to administer regular and emergency payments to patients and their dependent relatives.

ALWAYS KNOW THAT IPOPI IS THERE AS THE FRIEND AND SUPPORTER OF YOUR NMO!

The Global Office in Lisbon is only a Skype Call or e-mail away and the services are FREE to NMOs and Associate Members!