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EU PID Forum

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HTA

*technology. It takes into consideration the **medical, social, economic and ethical issues** related to the use of a health technology. The process aims to apply a systematic, transparent and unbiased approach when dealing with health technologies.*

Economics and Reality

...many being denied

- PID's are rare conditions and the accumulated evidence may not meet criteria for randomised clinical trials
- NO HTA for PID....Yet !

HTA – General Process

- Industry asked to submit data
- Clinicians asked to submit data
- Patient Organisations may submit data and make representations but not automatically asked or involved

HTA- Advantages

- Assists in decision making (but not a decision in itself)
- “*Fair comparison*” using a mathematical model

Insufficiently Considered

therapy such as regular IVIG.

- **Impact on education /employment**
Ability to receive an education, to work
- **Impact on family and on carers**
Time missed from work, impact on parents, siblings
- **Quality of Life**

Role of Patient Organisations

- work with doctors to provide evidence based data
- Contribute real experiential data:
 - treatment outcomes and benefits, surveys, case histories

Experiential data – Survey of 58 Young men with Haemophilia

Ireland	16.5	5	0.76
France	20.1	15	0.73

58 Young men from 20-35 years

Sweden – always treated with Prophylaxis

Noone D, O'Mahony B, Haemophilia (2010),
accepted for publication



Role of Patient Organisations

- We live in countries and in societies...not just in economies
- Nothing about us...without us

HEMOPHILIA ORGANIZATION DEVELOPMENT

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A health technology assessment
of prion filtration of red cell
concentrates to reduce the risk of
variant Creutzfeldt-Jakob disease
transmission in Ireland

26 January 2011

Safer Better Care

Patient Involvement

