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Advocacy in Action and Concepts in Factor Replacement Course, World Federation of Haemophilia, Paris, 12th-15th May 2011

Facilitators: Mohamed Aris Hashim- Malaysia WFH
Gordon Clarke WFH UK Haemophilia Society
Brian O'Mahony Irish Haemophilia Society
Bruce Evatt MD USA
Dan Farthing UKHaemophilia Society
Declan Noone Irish Haemophilia Society

Attendees : Representatives from National Member Organisations in Bulgaria, France, Germay, Hungary, Ireland, The Netherlands, Poland, Sweden, UK.

The Advocacy in Action program was launched in 2010 to help national patient organisations bring about change through advocacy and achieve a stronger voice for inherited bleeding disorders globally. Targets will be tailored to support the different needs and realities of National Member Organisations around the world. It is a 5 year program, with workshops based on specific issues. Sponsored by Baxter, Advocacy Project Grants and an annual award for outstanding progress in advocacy will be awarded.

Advocacy is the process of influencing key individuals, decision makers and organisations to maintain or achieve changes in their policies, practices and standards that affect people with bleeding disorders. Methods of Advocacy can include lobbying, education, raising awareness and using the media. Advocacy takes place at all levels of the decision making process where there are relationships (family, community, local, national, regional and international structures).

Initially we were alerted to the potentially damaging impacts of the global economic recession. We were instructed how to provide both qualitative and quantitative data, to advocate for the maintenance and further improvement of care. It was highlighted that this is the most effective method of advocacy. We looked at the nine definitive steps of advocacy and how these could be integrated into out National Member Organisations. A successful advocacy plan was presented by the Irish Haemophilia Society which outlined their strategy for opening their new Comprehensive care centre in Cork. There was a session on the importance of economics and health technology assessments (HTAs) and the necessity for patient organisations to be involved in these assessments.

The sessions on Collaboration were introduced by Gordon Clarke and Dan Farthing.
The nine advocacy steps :

- What do we want? (GOALS),
- Who can give it to us? (KEY PLAYERS, AUDIENCES, POWER HOLDERS)
- What do they need to hear? (MESSAGES),
- Who do they need to hear it from? (MESSENGERS)
- How can we get them to hear it? (DELIVERY)
- What do we have? (RESOURCES)

- What do we need to develop? (GAPS)
- How do we be begin? (FIRST STEPS)
- How do we tell it is working? (EVALUATION).

They highlighted the importance of collaborating with clinicians, Politicians and building networks and coalitions globally. It was stressed that decision makers use confusion as a reason not to take action. If everyone involved providing treatment and care is asking for the same thing and working together, we are harder to ignore. We also looked at developing an advocacy strategy in various countries and then we were divided into groups by country.
Dan and I had to devise a skeletal advocacy and lobbying strategy for the UK.
GOAL : Re open Skipton Fund to raise cut off point for claiming from 31st March 2010. We want it open ended so that widows can continue to claim.
KEY PLAYERS : Secretary of State for Health Andrew Lansley, Parliamentary under Secretary of State for Health Anne Milton, Clinicians, Parliamentary APPG, Skipton Fund Campaigners, Macfarlane Trust, Hep C Trust, British Liver Foundation.
Key players who will oppose the issue : Treasury, Department of Health budget constraints.
MESSAGES : Affordable, Public Support, 1 Message, no conflicting opinion, simple to implement, Equality of opportunity issue as there is no cut off date in Wales, Northern Ireland and Scotland.
DELIVERY of data: Realistic assessment of numbers of widows based on Wales, Scotland and Northern Ireland, UKHCDO look back exercise currently taking place, Take a public poll, Under Freedom of Information Act source original Skipton Fund projections.
This is ongoing and a first step to keep awareness of the contaminated blood issue.

The Concepts in Factor Replacement Course gave us a thorough insight into the history and current Factor replacement therapy globally. We also learnt about Biosimilars, which is the fastest growing segment of the pharmaceutical industrustry. Biosimilars are produced by living cells, often using recombinant technology. In the current financial climate, with increasing pressure on healthcare budgets biosimilars are less expensive copies of a drug product but are not required to include preclinical and clinical data, only demonstrate pharmaceutical equivalence and bioequivalence.

We were given an introduction to national tender systems including the steps in a tender process and a comparison between the systems used in several countries. The importance of formal involvement of knowledgeable clinicians and NMO representatives was stressed. In the UK to maintain clinical freedom and supply, more than one company is successful in the tender process. Dr Bruce Evatt took a session on Safety which provided an overview of the history and lessons learned from the past. We also examined current issues like inhibitors and prions.

Throughout the workshop we were divided into groups and were given case studies, skeletal plans, mock tenders and various worksheets to complete together with frequent brainstorming. Lynne Kelly