IPPOSI
Irish Platform for Patients' Organisations, Science and Industry

UPDATES FOR SHARING
W/E: 17TH FEBRUARY 2012

THE FOLLOWING INFORMATION HAS BEEN RECEIVED AND IS BEING SHARED FOR YOUR INFORMATION ONLY

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ITEM 1: OF PARTICULAR INTEREST TO IPPOSI PATIENT'S ORGANISATIONS MEMBERS

RECEIVED FROM: **AVRIL DALY, CHIEF EXECUTIVE FIGHTING BLINDNESS**

DATE: **14TH FEBRUARY 2012**

SUBJECT: **THE GOOD PRACTICES FOR THE COLLABORATION BETWEEN PATIENTS ORGANISATIONS AND CENTRES OF EXPERTISE / EUROPEAN REFERENCE NETWORKS - PLEASE COMMENT**

Dear All

One of the outcomes of the Polka project (a three year EU Funded project ended on 31 August 2011) was to develop guidelines on how patients' organisations could best work with Centres of Expertise on one hand and European Reference Networks on the other hand.

This was a continuation of the Eurordis 2008 action "Declaration of Common Principles on Centres of Expertise and European Reference Networks for Rare Diseases" (see attachment).

The good practices propose precise actions that patients' organisations could lead in liaison with their relevant Centres of Expertise and/or Reference Networks and the main points are as follows:

1. Basic Collaborative Support to facilitate partnership with Centres of Expertise/patients' organisations: what is considered essential, not optional
2. Additional Collaborative Support both for patients, their organisations and health care professionals: other activities that can be proposed optionally
3. Operational Support: for the day-to-day work of Patients' Organisations: support needed by organisations to deliver the activities they propose

These good practices derive from series of interviews with leaders of European Reference Networks, patients' representatives, a Delphi method to evaluate Centres of Expertise and the relations with

patients' organisations in the frame of the Polka project, from 2009 to 2011.

We are hoping to consult with Irish patient groups on these documents and would be most grateful if you could forward them to members of your organisation or individual patient contacts who may be interested in participating.

If you could send me any comments you may have before Friday 24 February I would be most grateful.

Thank you in advance.
Avril

Attachments:

DECLARATION.doc GOOD PRACTICE - ERN & PO.doc GOOD PRACTICE - COE & PO.doc

N.B.: IF YOU HAVE ANY COMMENTS OR QUERIES ON THE ABOVE PLEASE RESPOND DIRECT TO AVRIL DALY BY EMAIL: avril.daly@fightingblindness.ie OR BY PHONE: +353 1 709 3050

ITEM 2:

RECEIVED FROM: **JACKIE COTTELL – IRISH MEDICINES BOARD**

DATE: **FEBRUARY 2012**

SUBJECT: **IMB AND PDA CONFERENCE - ESOF SATELLITE CONFERENCE 'MAKING GENE AND CELL THERAPY MEDICINES A REALITY'**

Conference to be held in Dublin on the 10 - 11 July 2012, organised jointly by Irish Medicines Board (IMB) and the Parenteral Drug Association (PDA)-Ireland Chapter on the subject of cell and gene therapy.

The conference is entitled “Making Gene and Cell Therapy Medicines a Reality’ and will form a satellite meeting to the major international scientific event of 2012 – the European Science Open Forum 2012 celebrating Dublin as City of Science and taking place in the National Convention Centre in Dublin 11-15 July. IMB-PDA will also be running a session in the main convention centre on the same theme to suit the wider ESOF audience and the charge applied to the satellite will cover all costs for access to the ESOF programme.

THE IMB_PDA conference will focus on the science, technology and regulation of gene and cell therapies and will include speakers from academia, industry, government and patient representatives.

You can find details of the conference on the brochure and an application form below:

PDA IMB Conference 2012 Call for Posters

Meeting Registration Form.doc

PDA IMB ESOF Brochure Rev 2.pdf

N.B.: IF YOU HAVE ANY FURTHER QUERIES, PLEASE CONTACT JACKIE COTTELL DIRECT ON: esofsatelliteconference@imb.ie