

The new Pharma Disclosure Rules: the good and the bad things

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Patients Network for Medical Research and Health



EPF & EGAN Welcomes

- **The new Pharma Disclosure Rules**
- **As well as the AllTrials Transparency Initiative**
- **Although patient groups are not included**
- **Patient groups and EFPIA developed already in 2007 a Code of Practice (revised in 2011)**
- **EPF, partner in Guiding Principles for Good Governance in the Pharma Sector (DG Enterpr.)
(a series of principles and core ethical values for all stakeholders)**

Patients & Industry

- **A legitimate need to talk to each other:
we have the diseases, they make the drugs**
- **Nevertheless, patients are regularly being criticized for these relationships, even in the context of public-private partnerships, like in IMI**
- **Especially European Patient Academy (EUPATI)**
- **No clear policy – nor from the European Commission, nor from the EU Member States on how patient groups should be funded**

Cancer Congress Amsterdam, 2013

- **Patient advocate groups protest anachronistic Dutch Medicines Act at 2013 European Cancer Congress**
- Patient advocates from all across Europe, attending the European Cancer Congress on 27 Sep to 1 Oct 2013 in Amsterdam, represented by 70 patient advocates that have signed a petition during the congress, strongly object to the regulation which forbids patient advocates to enter the exhibition hall.



NO

NO

NO

NO

NO

NO

NO

NO

NO

NO

NO

ECCO 17 ESMD 38 ESTRO 32

The exhibition hall is accessible to Badgeholders with a blue bar only (Prescribers). Badgeholders without a bar (Non-prescribers) are not allowed in the exhibition hall.

Due to the multidisciplinary audience of this congress, and in line with applicable codes and particularly the Dutch Medicines Act concerning the promotion of prescription-only medicines, all participants will be provided a badge based on whether they are a prescriber or non-prescriber – according to the professional category one belongs to, disregarding their origin, nationality or where their professional license is held.

If you think you are wrongly badged, please go to the Exhibition Access desk located in the entrance hall near the entrance of the exhibition.



ECCO 33 ACR SGP

A man with short brown hair and a light beard is looking directly at the camera. He is holding a white rectangular sign in front of his chest. The sign has text printed on it. The top part of the sign says 'PATIENT ADVOCATES' in black, followed by 'IN' in large green letters. A horizontal line is drawn below 'IN'. Below the line, the sign says 'NOT OUT' in black and red letters.

PATIENT ADVOCATES IN

NOT OUT

For more information

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