

The image is a title slide for the EPF Spring Conference 2007. It features a light blue background at the top, which transitions into a pattern of overlapping circles in shades of purple, pink, and orange. The text is centered and reads "EPF Spring Conference 2007" in a large, bold, black font with a white drop shadow.

**EPF Spring
Conference
2007**

Who Really Represents Patients?

Mike O'Donovan, Board Member

20-21 March 2007

EPF Spring Conference

Can patient group speak for all patients?

Yes – Membership is not everything

1. You are in contact with a wide group of patients
2. Large numbers of patients access your services
3. Your organisation has democratic and consultative processes

Who validates information provided by patient organisations?

1. Medical / Treatment info' -> EXPERTS
2. Info' on patient experience -> RECIPIENTS
3. You can't control information patients access
4. You can make "Best efforts" to ensure quality sources
5. You can sometimes give "advice" rather than "information"

How to increase solidarity accross the European patients movement?

1. Individual organisations should lobby on issues specific to their condition
2. Organisations should be willing to identify issues common to several conditions and allow a single organisation to lead (EDF)
3. Organisations should understand large generic issues where an umbrella organisation can be most effecive (**EPF**)

Are consumer organisations and other stakeholders legitimate representatives?

1. Consumers organisations involved with health issues for many years
2. They have a right to comment particularly on “self treatment” where patients spend their own money
3. Patient organisations are the best representatives of patient interest
4. Medical professionals cannot represent patients just because they are “expert”
5. On occasions others can legitimately represent patients

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