

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**

# Are patient organisations viable and sustainable?

*Rodney Elgie*

20-21 March 2007

EPF Spring Conference

**26 patient organisations were present**  
**1 had a professional fundraiser**  
**1 had fundraising committee**  
**Absence of meaningful strategy**  
**Funding required for their existence**  
**A need to be credible, transparent, accountable**  
**and professional**  
**Highly motivated provides added value**

1. Collaboration not competition. Danger of creating bad press through wastage of funds
2. Avoid duplication – creates confusion – way fund?
3. Startup money obtainable, but sustainability more difficult
4. National – local money available, but EU funding more difficult
5. EPF could provide guidelines for fundraising and principles of funding

# Creativity

1. Tax relief across all EU member states
2. Use links with and to universities
3. Think about different actors, e.g. mental health employers
4. Use individuality of patient organisations as these will appeal to different people
5. Work with healthcare professionals
6. Be active in research – members are your greatest asset
7. Quantify the value of volunteers

## Conclusions

1. Hold workshop involving variety of stakeholders and funders from different sectors
2. Creation of an overarching foundation with independent board of trustees
3. Create EPF platform for develop extensive media campaign incorporating the views of stakeholders
4. Underline the added value of patient organisations within the health arena

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