



European Federation of
Allergy and Airways Diseases
Patients Associations



Winding-up of Conference

Description of a modern Patient Organisation

Ondřej Rybníček

Czech Initiative for Asthma

EFA Board Member



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SUCCESSFUL PATIENT ORGANISATION OF TODAY & TOMORROW

- A strong mission statement and high quality information provision
- Connections with other (national/international) patient organisations
- Connections with policy makers (national/international)
- Industry partners – more than just sponsors
- International projects - partnership working can increase the ability to influence and can offer additional funding opportunities

The Future of Patient Organisations
(Nicola Bedlington)

What constitutes a successful patient
organisation? (Jenny Versnel)



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SUCCESSFUL PATIENT ORGANISATION OF TODAY & TOMORROW

- Necessity to be innovative and to identify new opportunities
- Ensure a credible and professional service at all times
- Monitoring the impact of the work and communicating this to stakeholders
- Use of volunteers

The Future of Patient Organisations
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What constitutes a successful patient organisation? (Jenny Versnel)



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A STRONG MISSION STATEMENT AND HIGH QUALITY INFORMATION

- Helping Asthma Real Patients Project HARP (David Price, presented by Rob Horne)
- Definition and validation of „Minimal written information programme“, a requirement for asthma patient education, to improve asthma management in Italy (Giorgio Salerni)
- Finnish Allergy Programme – Current Status and Patient Involvement (Tari Haahtela)



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A STRONG MISSION STATEMENT AND HIGH QUALITY INFORMATION

- Voice of the Patients: Allergic Rhinitis is not a trivial disease (Susanna Palkonen, Erkkä Valovirta)
- Report of EFA working group in food allergy (Susanna Palkonen)
- Burning issues in Allergy: Identify the right content to deal with for patient organisations in the future to be relevant in solving problems for allergic peers, under the condition of a changing environment (Geir Endregard)



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NETWORKING WITH OTHER PATIENT ORGANISATIONS

- EFA Presentation to Global Alliance Against Respiratory Diseases (GARD) Leaders and Project Proposal (Marianella Salapatas)
- The new EFA Project - EFA beyond the borders of Europe (Marianella Salapatas)



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CO-OPERATE WITH POLICY MAKERS & HEALTH CARE PROFESSIONALS

- The Brussels Declaration: Change is needed in asthma management (Rob Horne)
- EU Food Labelling Directive Proposal and Allergy (Suzanne van Rokeghem)
- Allergology recognized as a medical speciality across Europe: Current status (Roy Gerth van Wijk)



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PARTNERSHIP IS A KEY!

- Strategic Alliances and Value of Partnerships with Health Care Professionals, policy makers, other NGOs and industry for modern Patient Organisations (Otto Spranger)



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Industry Partners – More than just sponsors

- **Platinum**

- GSK
- Novartis
- European Commission DG Research



- **Gold**

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- **Silver**

- Boehringer Ingelheim (Pending Contract)
- Linde Healthcare/ Remeo® EXAMPLE



- **Bronze**

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- **Other partners**

- Nigaard
- ALK Abelló (Pending Contract)



- **Ongoing negotiations with two more pharmaceutical companies to partner in 2009**



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INTERNATIONAL PROJECTS

- News from GA²LEN (Torsten Zuberbier)
- Co-ordination Action on Indoor Air Quality and Health Effects project EnVie (Matti Jantunen)
- Health & Environment Alliance HEAL & EFA joint Project:www.knowyourairforhealth.eu (Gill Erskine)
- U-BIOPRED project: Phenotype „handprints“ to identify severe asthma condition (Peter Sterk)
- Prevalence, Cost and Basis of Food Allergy in Europe (EuroPrevall) project (Ronald van Ree)



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Invitation to 14th EFA Conference 2010, Vilnius, Lithuania

- All EFA members are invited to prepare a slide for this conference – consequences of the learnings from Rome (deadline April 30, 2010)!!!
- EFA working groups – active participation of all EFA members is welcome!!!



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Winding-up the Conference

Thank you for your attention!

