

“Do’s and Don’ts”

presenting the paper to policy makers



Lene Jensen,
Rare Diseases Denmark

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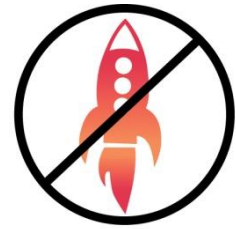
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Three pieces of advice



You need to have a problem, before you solve it

- What is your platform on fire? Identify your problem(s)
- Document it well! And be authentic

You need to ask for something in order to get it

- References to general rights are appropriate, but not enough...
- Your suggestion / request / demand need to be concrete!

Make alliances!

- Get back up from professionals and others

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Succes!! (not the sofa, the pillow!)



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11.30 – 13: Setting the priorities

Group 1 – Clara – problems: Lack of politics and structures

Focus on reco headers 1 and 10, with a total of 5 specific reco's

Group 2 – Mandy – problems: Lack of national plan and lack of coordination. Focus on reco headers 2 and 4, with a total of 8 specific reco's

Group 3 – Valentina – problem: Lack of knowledge. Focus on reco header 3 with a total of 5 specific reco's

Group 4 – Ivana – problems: Lack of influence and need for capacity building. Focus on reco headers 5 and 9 with a total of 8 specific reco's

Group 5 – Eleni – problems: Lack of acces to social services, protection and employment. Focus on reco headers 6 and 8, with a total of 9 specific reco's

Group 6 – Maria – problem: Lack of recognition and compensation

Focus on reco header 7 with a total of 7 specific recommendations

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Afternoon: Panel of stakeholders

Moderator: Lene Jensen, Rare Diseases Denmark

Encarna Guillen-Navarro @encarna_guillen, *Hospital Clínico Universitario Virgen de la Arrixaca; former Regional Health Minister of Murcia, Spain* – roles: health care provider; policy maker

Emilia Severin, *Researcher, Department of Genetics of the Carol Davila University of Medicine and Pharmacy, Romania* - roles: academic/researcher; policy maker

Mandy Andrews @mandynetwork, *International Foundation for Integrated Care, Scotland* – roles: policy maker, improvement perspectives

Victoria Hedley @RareDiseasesEU, *University of Newcastle, UK* – roles: ERN coordinator, academic, policy maker

