

## MEMO

To: **EURORDIS National Alliances, Organisers of EUROPLAN National Conferences**  
From: **EURORDIS Advisory Group**  
Date: **27 November (update of the Memo dated 9 June 2009)**  
Re: **LAYOUT and PRACTICAL INFORMATION on the organisation of EUROPLAN's National Conferences**

This Memo aims at giving you (or recalling) some practical information on the **organisation** and **layout** of the National Conferences of EUROPLAN. It is based on the first Memo sent on June, 9<sup>th</sup>, 2009, to the Alliances organising a National Conference in the framework of EUROPLAN, but it is had been updated with the results of the most recent discussions at the last CNA meeting (Paris, 5<sup>th</sup> November 2009) and the developments related to the project in the last months.

### 1. ADVISORS

Your relations as far as this project is concerned continue to be mainly with the Advisor who is working with each of you. To recap on the **Advisors** and the countries they are in charge of:

Britta Berglund :	<ul style="list-style-type: none"><li>• Denmark</li><li>• Sweden</li></ul>
Mirjam Mann :	<ul style="list-style-type: none"><li>• Germany</li><li>• Netherlands</li></ul>
Christel Nourissier :	<ul style="list-style-type: none"><li>• France</li><li>• Luxembourg</li><li>• Croatia</li></ul>
Avril Daly:	<ul style="list-style-type: none"><li>• Ireland</li><li>• UK</li></ul>
Simona Bellagambi :	<ul style="list-style-type: none"><li>• Italy</li><li>• Greece</li><li>• Spain</li></ul>
Dorica Dan :	<ul style="list-style-type: none"><li>• Romania</li><li>• Hungary</li><li>• Bulgaria</li></ul>

We invite you to continue to have regular contacts with your Advisor. Please feel free to copy Valentina (EURORDIS) in your correspondence with your respective Advisor when you deem useful: [valentina.bottarelli@eurordis.org](mailto:valentina.bottarelli@eurordis.org)

## 2. OBJECTIVES OF THE CONFERENCE

The EUROPLAN National Conferences aim at taking the necessary steps towards outlining a high quality National Plan on RD with concrete objectives in each field. The Conferences will therefore aim at gathering all relevant stakeholders at the national level in the field of RD keen to find consensus to advance the development/fine-tuning of the National Plan (depending on the situation of the country).

Ultimately, the Conference aims at helping patients with RD have a better life by promoting or improving national strategies, including those elements which may integrate with the EU policy on rare diseases. In fact, National Plans for RDs are effective instruments to improve life of people affected by RDs.

## 3. PARTICIPANTS

- All national stakeholders in the field of RDs are target invitees of the National Conference. These include patients and their families, representatives of patient organisations and national alliances, academics and scientists, healthcare professionals, carers and social workers, public authorities, etc.

## 4. FORMAT of the CONFERENCES

- The National Conferences will be configured in Plenary Session and Workshops. The Workshops will be set up according to specific topics (“Themes”) and will be responsible to deliver concrete proposals for the Plenary. This will be an essential task, as the **Conference is meant to be outcome-oriented**.
- The Conference should preferably be planned as a one-day or a two-day Conference. The first option is recommended if considered more suited for financial and/or organisational reasons.

In a 2-day format, the structure would be as follows:

- 1<sup>st</sup> Morning Session: Plenary Session - Presentation of European Commission Communication, the EU Council Recommendation and Recommendations of EUROPLAN
- 1<sup>st</sup> Afternoon Session: First Half of Workshops
- 2<sup>nd</sup> Morning Session: Second Half of the Workshops

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- 2<sup>nd</sup> Afternoon Session: Presentation of the Results of the Workshops - Plenary Debate - Possibility of adopting some common statements, list of goals or similar.
  - During the **Plenary Session**, the EU documents (Commission Communication and Council Recommendation on RD) must be presented. A slot will be also dedicated to the presentation of the EUROPLAN Recommendations.
  - The **Workshops** are linked to the chapters or themes of the Council Recommendation on Rare Diseases<sup>1</sup>. There will be a Workshop on each Theme: 1) Methodology and Governance of a National Plan; 2) Definition, codification and inventorying of RD; 3) Research on RD; 4) Standards of care for RDs - Centres of Expertise / European Reference Networks; 5) Patient Empowerment. For more details on the Workshops' Themes, please see the separate document "*091127 Concept Outline of EUROPLAN National Conferences*".
  - The two additional Themes of the EU Recommendation (5) Sustainability and (6) Gathering expertise at the European level, will have to be addressed within the Workshops from 1 to 5. Naturally, you would be free to organise more Workshops, either by splitting up part of the Themes, addressing "Sustainability" or "European networking" separately, and/or by adding topics of particular interest to your country. The only limitation is that you should be able to answer the basic questions on all 7 Themes and adhere to the structure of the Report template.
  - Workshops should be moderated by a competent person, so to ensure that conclusions are drawn and correctly reported. This could be a **Chair and/or a Rapporteur**. Ahead of the Conference, they will have to prepare a working document, possibly in a PowerPoint format, based on specific proposals, which will be then discussed and amended as necessary by the Workshop and eventually presented to the plenary by the Rapporteur. Therefore, the Chair and the Rapporteur will have a pivotal role and it is important that they are carefully selected, ideally among experienced and technically prepared patients.
  - It is extremely important that, as much as possible, a **representation of all stakeholders** is ensured in all Workshops, so that they all can take ownership of the outcomes of the Workshops. In order to do so, it is important that the discussions and the programmes of all Workshops are attractive for all sorts of stakeholders. In particular, we need to make sure that not only patients attend the Workshop on Patient Empowerment, but also national authorities, healthcare professionals, etc., so that solutions are found together, under the reciprocal responsibility.
  - **Speakers'** interventions in plenary should be limited to the essential in order to leave as much space/time as possible to the Workshops to discuss and develop in detail the proposals for their respective Themes.

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<sup>1</sup> COUNCIL RECOMMENDATION of 8 June 2009 on an action in the field of rare diseases (2009/C 151/02)

- **Patient testimonials** should be invited to speak in the Workshops, in accordance with the Themes that will be discussed in each of them.

## 5. STEERING COMMITTEE

- A **Steering Committee** in charge of the preparation of the Conference will be established, in which at least a representative of the Health Ministry takes part in order to facilitate dialogue with government and ensure their support. Nevertheless, if in certain countries this participation is not suited or not possible, practical ways of involving national authorities may be found which are low key or less formalised.
- In order to allow effective decision-making, ideally the Steering Committee should be composed of no more than 6 members. However, national circumstances may suggest that a different, even larger composition is preferable; hence the Committee will be created accordingly.
- The Advisor responsible for the Conference and at least one representative of the National Alliance organising the Conference must be appointed members of the Steering Committee and will participate to its meetings.
- The other members of the Steering Committee will be appointed in order to reflect the content of the National Conference and to ensure a balanced representation of all stakeholders, e.g. government, scientists and healthcare practitioners, ideally from Centres of Expertise.

## 6. TIMING

- The **Conferences need to take place in 2010** and will be spread over the year in order for the Advisors and EURORDIS staff to be able to offer the necessary support. Please keep your Advisors updated on the planning as the Conference organisation moves on, as she needs to gather this information for a general overview and exchanges with the other Advisors.
- As you are probably aware, meeting facilities for this kind of Conferences need to be reserved well in advance. Please consider this a top priority if you have not done it.
- Also, if you have not done it yet, please start addressing your favourite speakers and Chairs now. Please use the Content Outline (separate document) to identify them.
- As soon as available, we will give further information on how the EUROPLAN Recommendations will be presented. This needs to be confirmed, but we are striving to make sure that this part is presented by a native speaker (or the language that you wish to offer in your Conference).

## **7. COMMUNICATION WITH PUBLIC AUTHORITIES**

- The **communication with public authorities** will have to be made on a one-to-one basis, each NA with their own country's competent authorities.
- Nevertheless, in order to ensure consistency of messages, we sent in the past months a draft letter for you to use with national authorities, but also sponsors or others, as you deem appropriate, which you can, where necessary, adapt to national circumstances.
- Additional communication will be ensured: EURORDIS will develop a EUROPLAN brochure which will be used by all project's partners to communicate on the project with different audiences. Moreover, updates on the EUROPLAN project, the National Conferences and National Plans will be posted on the upcoming Rare Disease Blog and the EURORDIS e-newsletter.

## **8. REPORTING**

- Conference organisers must deliver a final report of the National Conference in English. To this aim, you will have to assign a dedicated person able to work in English who will provide the first draft of the final Conference report in accurate English and will work with the Advisor to fine-tune the report. Please inform your Advisor on who is going to be this person as soon as possible.
- The template of the report is being developed and will be provided in due time.