



**EURORDIS**

European Organization  
for Rare Disorders

Paris, July 9th, 2001

To : R. Gérard Alliance Maladies Rares Belgium  
G. Hebeltoft DARD – Danish Association of Rare Disorders  
Y. Huizer VSOP – Netherlands  
M. Lipucci di Paola UNIAMO Federazione Italiana Malattie Rare  
C. Nachtigaller Rare Disorders Germany – BAGH  
C. Nourissier Alliance Française Maladies Rares  
R. Sanchez de Vega FEDER – Federacion Espanola de Enfermedades Raras  
S. Silva ANFQ – Portugal  
E. Wallenius Sallsynta Diagnostiser – Swedish Association of Rare Disorders  
C. Youngs Rare Disorders Alliance – UK

From : G. Arduin EURORDIS

CC : T. Andersen EURORDIS  
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**Guidelines for next National  
Workshops – PARD I**

Dear all,

After the successful European workshop in Brussels last June, we are now entering into the beginning of the phase IV of the project. I hope you have all recovered from these 2 dense working days.

All the 7 national alliances and the 3 potential alliances will have to develop one day national workshop which should be scheduled between mid-September and mid-October 2001.

This last workshop has several objectives :

- ◆ To give feedbacks to all the participants present at the national workshop (January/February 2001) about the development of the European workshop in Brussels and make analysis.
- ◆ To review the draft final report for the EU that we will send you early September, in order for you to comment, make suggestions and improve the report. This part is essential as it is for you the opportunity to check that the report does not contain major misunderstanding but also that you agree with the final conclusion which we are suggesting.
- ◆ To suggest action plans of national recommendations in your country .

**Structure** : 1 day workshop at national level in Denmark, France, Germany, Italy, Spain, Sweden, UK and in Belgium, Netherlands, Portugal.

**Participants** : 6 representatives of patients associations, 2 medical doctors, 1 coordinator in each national alliance, representatives of Health Ministry, Pharmaceutical Industries.

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**Outcome** : Analysis of European meeting, reporting to other patients associations representatives, recommendation paper on actions to be implemented in your country, feedback on the draft final report.

As for the first National workshop, could you please send me an agenda of your workshop and list of participants **no later than August 30<sup>th</sup>, 2001**. Those agendas will be reviewed in a steering Committee on September 3<sup>rd</sup>, 2001.

You will also find enclosed a planning of activities in the next coming months which should be respected by each National Alliance, for the good continuity of the project.

I encourage you to send us your travel expenses request form for your group (one request per country) regarding the trip to Brussels, as soon as possible, if you haven't done so yet.

If you need further information or any specific assistance, please contact the office.

In the meantime, I wish you all nice summer holidays.

Sincerely

Guilaine Arduin  
Executive Director

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