COMMON FORMAT
National Conferences "EUROPLAN II" (2012-2015)

This Memo is addressed to EURORDIS National Alliances and patient groups responsible for the organisation of National Conferences on Rare Diseases. It aims to provide **practical information** on the **organisation** and **format** of the National Conferences of EUROPLAN.

It is based on the Layout Document developed for EUROPLAN I (2008-2011) as the basic conferences' format has not conceptually changed in EUROPLAN II. Yet, in the proposed format some elements have been modified and additional features added following the experience of the 15 "EUROPLAN I" Conferences and the feedback received from patients and organisers, as well as EURORDIS-EUROPLAN Advisors.

Contents

BACKGROUND

Objective of the EUROPLAN National Conferences

The objective of the EUROPLAN National Conferences is to **assist the development and/or implementation of high quality National Plans or Strategies for Rare Diseases (RDs).**

The Conferences will therefore aim to gather all relevant stakeholders at the national level in the field of RD, to find consensus to advance the national policy on RD. Depending on the status quo in each country, this may imply: developing; fine-tuning; implementing; assessing the first National Plan or Strategy on Rare Diseases; or even defining a further (second, third) Plan.

The EUROPLAN National Conferences are organised by National Alliances of RD patients' organisations (NAs) or a strong patient organisation at national level if a NA does not exist. They are partners of EURORDIS in the EUROPLAN project.

The success of EUROPLAN National Conferences lies in the adoption of a common methodology and a common format by conferences' organisers to address key issues relevant for rare diseases patients in European countries and foster the implementation of concrete measures / policies at the national level. While implementing a common format reflects the common European policy guidelines, there is a degree of flexibility of this format to respond to national needs and specific situations.

Ultimately, the Conferences aim to help 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. National Plans for RDs are effective instruments to improve the lives of people affected by RDs.

"EUROPLAN 2": From March 2012 to August 2015

15 EUROPLAN National Conferences were organised in the EU within the European co-funded project "EUROPLAN" (2008-2011). Most of these Conferences took place in 2010, one took place in January 2011 in Ireland.

Following the success of these Conferences, the organisers (NAs or strong national patient organisation) expressed their willingness and need to organise a second EUROPLAN National Conference to accompany the process of developing and adopting a national plan for RD in their Country.

The Joint Action “working on Rare Diseases” of the EU Committee of Experts on Rare Diseases (EUCERD) was launched in March 2012 and will end in August 2015.

The Work Package 4 (WP4) of the EJA is dedicated to advancing national RD policy and is led by Dr. Domenica Taruscio from the Italian Institute for Health (ISS) in Rome and EUCERD member.
The WP4 is divided in two parts:

1) The ISS team is in charge of providing technical support to policy makers for developing and implementing national plans or strategies on rare diseases through a capacity-building programme;
2) The EURORDIS team is in charge of coordinating the organisation of 25 EUROPLAN National Conferences, 20 in the European Union, and 5 in non EU countries. EURORDIS Staff is assisted by 10 EURORDIS-EUROPLAN Advisors.

EURORDIS-EUROPLAN Advisors

The main points of contact for Conference Organisers are the EURORDIS-EUROPLAN Advisors (hereafter “Advisors”) who are assigned to assist each National Alliance organising a EUROPLAN Conference. These Advisors are all from a National Alliance and have been selected by EURORDIS following an expression of interest. Throughout all phases of the conference organisation (as described in the paragraphs below), **Advisors are the reference persons and they can help in different ways:**

- → They keep regular contacts with their designated NA and with EURORDIS;
- → They answer all your questions on all aspects of the Conference organisation (content, layout, format, etc.);
- → They assist the organisers to design a tailor-made programme;
- → They may organise two visits to the host country before the Conference (or after if necessary);
- → They may provide a one day training course on how to organise a EUROPLAN Conference.

Conference organisers are invited to establish and maintain regular contacts with their Advisor. Please feel free to copy Ariane and Valentina (EURORDIS) in your correspondence with your respective Advisor when you deem useful: valentina.bottarelli@eurordis.org, ariane.weinman@eurordis.org .

STEERING COMMITTEE OF EUROPLAN NATIONAL CONFERENCES

Like any conference, the preparatory work is essential for the success of the EUROPLAN National Conference. Starting early is a great advantage and timely planning essential like in any project management. The first essential step in the conference organisation is to set up a **Steering Committee**. All of the preparatory works of the conference shall be endorsed by the Steering Committee.

Steering Committee - composition

- The National Alliance organising the EUROPLAN National Conference should establish a Steering Committee to oversee the preparation of the Conference. Ideally a representative of the Health Ministry should be involved in the Steering Committee in order to facilitate dialogue with government and ensure their support. Nevertheless, if in certain countries this participation is not appropriate or is not possible, practical ways of involving national authorities should be explored which are less formalised., It is important that the national representative involved in the ISS capacity-building programme be invited to be part of the Steering Committee.
- In order to allow effective decision-making, ideally the Steering Committee should be composed of no more than 5 or 6 members. However, national circumstances may suggest that a different composition is preferable.
- At least one representative of the National Alliance organising the Conference as well as the Advisor responsible for the Conference must be appointed members to the Steering Committee and will participate in its meetings. When the Advisors cannot speak the organisers' language, the latter should ensure that translation into English is provided at all relevant meetings.
- The other members of the Steering Committee will be appointed in order to reflect the content of the EUROPLAN National Conference and to ensure a balanced representation of all stakeholders.
- The Chair and secretariat of the Steering Committee should belong to the organising National Alliance (or patient organisation).

Steering Committee – main tasks

- The Steering Committee along with the main conference organisers (NA) shall perform the following actions in preparation to the conference:
  - **Identifying the location**; ensuring that the chosen location is available and book as soon as possible. Consider the accessibility of premises for disabled attendees.
  - **Identifying the best possible date**; see comments made in "How to attracts stakeholders", paragraph on timing; be careful that the conference does not conflict with other major events; assess the national political agenda carefully in order to make sure that the Conference outcomes can usefully feed into the policy debate.
  - **Identifying Speakers, Chairs of workshops and Rapporteurs**; identify competent people for each policy area from your member organisations and existing contacts; utilise the contacts of the other members of the Steering Committee to ensure a range of knowledgeable speakers from different stakeholder groups.
  - **Sending invites and advertising the Conference**; use all channels of usual communications, but extend to less used ones for a more complete outreach ; make sure that all different members of the Steering Committee use their own media to address prospective participants and send individual, targeted invitations where is more appropriate.
  - By far **the main task that the Steering Committee is expected to perform is the development of the conference programme.** Please read the section below "Developing the Programme" for the relevant details.

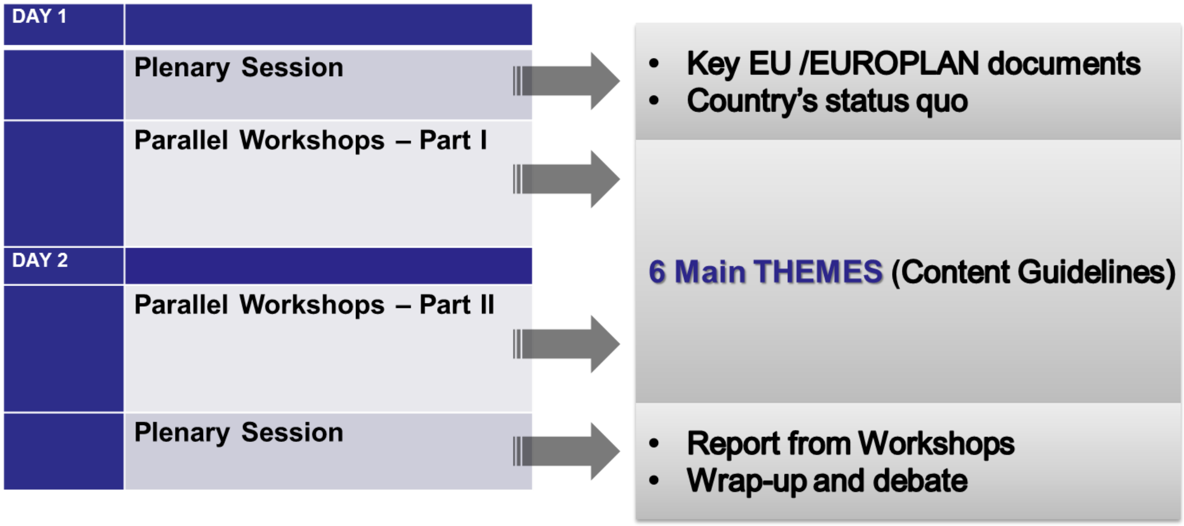
DEVELOPING THE PROGRAMME

The 25 EUROPLAN National Conferences share a common format. The conference organisers with the Steering Committee are responsible for designing a conference programme based on this common format that is adapted to a certain degree to the national situation. The common format is described below.

Common Format of the EUROPLAN II National Conferences

- **The EUROPLAN National Conferences will be configured in Plenary Session and Workshops**. The Workshops will be set up according to topics linked to the themes developed in the EU Council Recommendation on an action in the field of Rare Disease (see below “Workshops”). Each Workshop will 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 could be more suitable for financial and/or organisational reasons.

  Ideally, in a 2-day format, the EUROPLAN National Conference would be configured as follows:



DAY 1

Plenary Session
- Key EU /EUROPLAN documents
- Country’s status quo

Parallel Workshops – Part I

DAY 2

Parallel Workshops – Part II

6 Main THEMES (Content Guidelines)

Plenary Session
- Report from Workshops
- Wrap-up and debate

- A one day format would have a similar configuration, with plenary sessions both at the beginning and at the end of the day, which would be centred on the Workshops.

- Please refer to Annexes to this document for examples of programmes of EUROPLAN National Conferences that took place in 2010:

Annex I: Agenda of the EUROPLAN Polish National Conference , 22 October 2010

Annexe II: Agenda of the EUROPLAN UK Conference, 16 November 2010

Annexe III: Agenda of the EUROPLAN Greek Conference, 26-27 November 2010

Plenary Sessions

- During the Plenary Sessions, the main EU and EUROPLAN documents (Commission Communication and Council Recommendation on RD, EUROPLAN Recommendations and EUROPLAN Indicators) must be presented. However, in EUROPLAN II conferences it is important that the new (i.e. adopted after 2010) essential European documents are introduced, notably:
  - The EUCERD Recommendations on Quality Criteria for Centres of Expertise for RD in Member States: http://www.eucerd.eu/?post_type=document&p=1224
  - The EUCERD Recommendations on CAVOMP: http://www.eucerd.eu/?post_type=document&p=1446
  - The EUCERD Recommendations on European Reference Networks (ERNs) - to be adopted in 2013;
  - The EUCERD Recommendations on Rare Disease Patient Registries - to be adopted in 2013.

- In **plenary**, it is also advisable to schedule a presentation on the national status quo and most recent developments of national RD policy.

- A **wrap-up plenary session** at the end of the Conference should allow the participants to share the outcomes of the Workshops with the whole audience. Time should be reserved for a conclusive debate.

- **Speakers'** time in plenary should be limited to the essential in order to leave as much time as possible to the Workshops and to discuss and develop in detail the proposals for their respective Themes.

- **Translation**. Translation is not required in EUROPLAN National Conferences, however the organisers must provide translation service in English for the Advisor attending the Conference if he or she cannot speak the Conference language.

Workshops

- The **Workshops are the core part of the EUROPLAN National Conference**. The topics discussed in the Workshops are linked to the chapters or themes of the Council Recommendation on Rare Diseases[1], of the EUROPLAN Recommendations and EUROPLAN Indicators.
- For **EUROPLAN II** Conferences, the list of Themes has been updated from EUROPLAN I to also reflect the most recent developments in the field of EU/national RD policy and take into account the experience of EUROPLAN I Conferences.
- The **Themes** of the EUROPLAN II National Conferences are as follows:
  1. **Methodology and Governance of a National Plan;**
  2. **Definition, codification and inventorying of RD + 2.1) Information and Training;**
  3. **Research on RD;**
  4. **Care - Centres of Expertise / European Reference Networks/Cross Border Health Care;**
  5. **Orphan Drugs;**
  6. **Social Services for RD.**

- **Horizontal themes** are spread out through the 6 different Workshops**:**
  - **Gathering expertise at the European level;**
  - **Sustainability;**
  - **Patient Empowerment.**

In practice, questions concerning how to empower patients, how to fund different actions and policies (sustainability) and collaboration at supranational level (gathering expertise at EU level) will be dealt with in each of the 6 Themes with specific questions (see Content Guidelines).

For more details on the Workshops' Themes, please see the "**Content Guidelines**", provided separately to conference organisers. The Content Guidelines address all 6 Themes and present a **compilation of relevant questions covering many aspects of the same Theme**.

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[1] COUNCIL RECOMMENDATION of 8 June 2009 on an action in the field of rare diseases (2009/C 151/02).

The **conference organisers with the respective Chairs and Rapporteurs and the support of their Advisor will select in the "Content Guidelines" the key questions that need to be addressed in each Workshop**. This selection should be made taking into account the specific situation of the country at the time of the conference, the status of the rare disease policy in the country and the most pressing needs challenges that may result from this. **The selection of questions is therefore essential as it allows designing a programme tailored to the country's state of affairs in the field of rare diseases**.

- **Organisers are free to organise more Workshops**, either by:
  - → splitting up the Theme (for instance, Theme 2 has a separate part 2.1. on Information and Training; or Theme 4 has dedicated questions on Newborn Screening and Genetic Testing), or
  - → addressing separately Horizontal Themes, such as e.g. "Sustainability" or "Patient Empowerment"; and/or
  - → adding topics of particular interest to their country. The German EUROPLAN Conference in 2010, for instance, had a dedicated Workshop to "Monitoring" and some 2010 Conferences held workshops on Orphan Drugs, which in EUROPLAN I was not a separate Theme.

  The only limitation is that organisers should be able to answer the basic questions on all Themes and adhere to the structure of the Report template.

- As a reminder, the **methodology of the EUROPLAN National Conferences has been developed to ensure that all essential policy areas affecting rare diseases are addressed in a comprehensive way. As a result, it is very important that all identified 6 Themes are addressed in each Conference.**
- However, the **organisers of a second EUROPLAN National Conference may decide not to organise a Workshop on one of the 6 essential Themes** when they believe that:
  - The workshop's Theme has been exhaustively dealt with in the first EUROPLAN Conference and no additional elements could be brought in the discussion;
  - The Workshop's Theme could be better covered in another Workshop. In this case, it is important to demonstrate that the key questions will be discussed in the other Workshop.
- **If the Conference is the first EUROPLAN National Conference to be held in that country, all Themes should be discussed in dedicated Workshops.**

These arrangements –as well as the selection of key questions for the Workshop discussion - need to be discussed with the Advisors. Furthermore, they need to be discussed and validated with EURORDIS, who will consider whether the overall programme is in line with the EUROPLAN methodology.

Chairs and Rapporteurs

- Chair and Rapporteurs have an essential role in EUROPLAN National conferences' Workshops. It is important that they are carefully selected, ideally among experienced and technically prepared patients' representatives.
  - **Workshops' Chairs** are responsible to ensure the smooth running of the Workshop and that all key questions are addressed. They should have the necessary skills to facilitate discussion between a diverse range of stakeholders.
  - **Workshops' Rapporteurs** take notes and report in plenary the outcomes and proposals of the Workshop. They are appointed to ensure that conclusions are drawn and correctly reported.
- Ahead of the Conference, Chairs/Rapporteurs will have to prepare **background slides** based on the questions selected for each Workshop from the **Content Guidelines.** The slides will form the backbone of the Workshop discussion. EURORDIS will provide **template slides** that the organisers will pass on to Chairs and Rapporteur for filling in with selected questions and translating into the national language. The slides can be integrated with the outcomes of the Workshop discussion and eventually presented to the plenary by the Rapporteur.
- 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 order that solutions are found together.
- **Patients** could be invited to give their testimonies in the Workshops, in accordance with the Themes that will be discussed in each of them.

Timing

- **EUROPLAN II National Conferences should take place in 2013 and 2014. Early 2015 is also a possibility, if necessary**. In any case during the duration of the project (March 2012 – August 2015). For the sake of better organisation of the work of the Advisors, the dates of the Conferences should be defined in a way to allow for the Advisors and EURORDIS staff to be able to offer the necessary support. For this reason, Advisors shall be updated on the planning as the Conference organisation moves on, as they need to gather this information for a general overview and exchanges with the other Advisors.

- As mentioned above, please consider that meeting facilities for this kind of Conferences need to be reserved well in advance. This should be a top priority if you have not done it.
- For all relevant tasks, please make sure that you plan in advance, with the support of the Advisor.

Selecting and inviting participants

- All national stakeholders in the field of RDs are target invitees of the EUROPLAN National Conference. These include:
  - patients and their families
  - caregivers
  - representatives of patient organisations and National Alliances
  - academics and scientists
  - healthcare professionals
  - social workers
  - public authorities and politicians (national, regional and/or local, as appropriate)
  - EUCERD member(s)
  - industry and their associations
  - insurers
  - managers of centres of expertise
  - managers of respite care centres or recreational programmes
  - learned societies
  - partners of the EUCERD Joint Action, of which EUROPLAN is a component.

- It is left by the organisers' discretion to identify the prospective participants of the conference. However, it should be kept in mind that:
  - **EUROPLAN National Conferences are multi-stakeholder** Conferences (and not only patient-based);
  - as a minimum, a meaningful representation of the following must be ensured: patients and patient groups, competent public authorities, healthcare professionals, partners of the EUCERD Joint Action.
- Conference organisers /Steering Committee will assess what target groups of national stakeholders should be invited. They shall define the list of invitees and make the actual invitations, according to contacts that each of them may have.

Attracting stakeholders

- Hosting a dynamic and well-attended conference depends on a number of factors, including solid organisational skills and identifying appropriate partners. Please find below a list of elements that could be relevant to take into consideration:
  - → **Design an attractive programme.** Although EUROPLAN National Conferences have a predefined format and shared content that need to be respected, the programme of the conference should be made attractive by highlighting topics that are hot on the national agenda. In countries where a EUROPLAN National Conference is being organised for the second time, it is important that timely and relevant topics are on the agenda.
  - → **Explain the added value and uniqueness of EUROPLAN National Conferences.** Promote the interactive participation and learning opportunities that these Conferences provide. Also, promote the bottom-up approach to influencing decision-making. **All participants are also "decision- makers for a day**", because they have an exceptional opportunity to meet with all stakeholders to decide on how to shape their national policy on RD.
  - → **Consider timing**. Before deciding the date of your Conference, the public political agenda should be examined carefully. It should not collide or overlap with other similar events in the country. Also, it makes sense to take into account important events on the national calendar (e.g. elections), but also milestones in the RD policy (e.g. forthcoming release of the National Plan or an important piece of legislation). The EUROPLAN National Conference could be the preparatory event to a significant milestone in the development of the national RD policy … or the event where stakeholders discuss and take stock of the latest accomplishments.
  - → **Make the most of your connections**. Mobilise your Alliance or patient groups as well as partnering organisations and members. Ensure that all members of the Steering Committee get involved in identifying participants (as well as moderators and speakers). If necessary, ask for endorsement to third party. EURORDIS could provide this endorsement where it can be useful.
  - → **Use word of mouth and promote the Conference via member groups and associations**, but also Centres of Expertise and other institutions that may provide a useful relay. Take the opportunity to advertise the conference, or identify speakers at other events on RDs in general or specific disease conferences/seminars.
  - → **Use the appropriate communication tools to reach out target groups**. Using printed information or invites could be useful with more traditional audiences, whereas for others using social media, blogs and online patient communities may prove more effective.

Communicating the Conferences to 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, EURORDIS may provide upon request a draft letter for you to use with national authorities** (and other stakeholders), which can be adapted to national circumstances.
- EURORDIS will also facilitate communication with the representatives of national authorities involved in the part of the EUROPLAN project led by the Italian Institute for Health (ISS). The ISS is developing a capacity building programme as a part of EUROPLAN II and they identified a group of representatives of national Health Ministries. As the EUROPLAN National Conferences and the capacity building programme are closely interconnected, it is essential to try to involve these representatives of national authorities in the organisation of the Conference, notably in the Steering Committee. In some countries, these representatives are also EUCERD members.

  This list of EUCERD members can be found on the Committee's website in the section "about EUCERD": www.eucerd.eu
- Additional communication and tools that can support the promotion and the organisation of EUROPLAN Conferences:
  - → regular updates on the EURORDIS electronic weekly e-News**;**
  - → the EUROPLAN brochure developed by the ISS for the EUROPLAN 2012-2015 project: http://www.europlanproject.eu/_newsite_986987/Resources/flyer/EUROPLAN.pdf **;**
  - → updates on the EUROPLAN project, the National Conferences and National Plans will be posted on the EURORDIS Rare Disease Blog to which you are invited to contribute: http://www.rarediseaseblogs.net/.

Other aspects to take into consideration

- The experience of EUROPLAN I has identified a number of potential challenges that National Alliances may face:
  - → **Financial issues.** National Alliances or patient organisations may struggle to find funding sources to support the Conference. Although the EUROPLAN National Conferences are co-funded by the EUCERD Joint Action on rare disease and EURORDIS, these funds may prove insufficient to organise a nation-wide event. Previous experience (EUROPLAN I) has shown that conference organisers have been rather **creative in finding additional sources of funding**, which included: in kind contribution or donations, one of the most popular being free use of the conference venue; or obtaining support from sponsors.

- **Involvement of multi-stakeholder partners.** As noted above, EUROPLAN National Conferences should be multi-stakeholder events, although the main organisational responsibility lies with the National Alliances. In order to involve different stakeholders in the preparation of the Conference, it is important to develop tools or occasions for them to meet. For instance, the creation of a virtual platform or "virtual office" facilitates sharing documents and working remotely.

- **Getting familiar with key documents**. Conference organisers must be well acquainted with the key documents that will be presented and discussed at the EUROPLAN National Conferences.

  For instance, the NAs/ Conference Organisers must be familiar with essential European policy texts for Rare Diseases including the Commission Communication as well as the Council Recommendation on Rare Diseases and EUROPLAN Recommendations emerging for the EUROPLAN I Project, as well as EUCERD Recommendations.

  In addition, Advisors and EURORDIS Staff provide NAs/ Conference Organisers with **common Content Guidelines for all EUROPLAN National Conferences**. These Content Guidelines provide necessary documents by area (e.g. orphan medicinal products, research, etc.) and relevant questions to be addressed during the Conferences).

  Getting familiar with the documents is also important to identify speakers and chairs.

  All these documents are provided on the EURORDIS website in the section: "National Rare Disease Policy": www.eurordis.org.

- **Preparatory training.** In their mission, Advisors visit the National Alliance they assist in order to help design the programme of the conference. In addition, upon request, they can also provide a one-day training on how to organise a EUROPLAN National Conference. The prospective trainees are members of the Alliance and other patients. The purpose of the training is to illustrate the main features, steps and other requirements, with a view to solve practical and conceptual problems that may arise. The training would be interactive and should respond to the actual needs of each organiser.

AFTER THE CONFERENCE

Reporting

- Conference organisers must deliver a final report of the EUROPLAN National Conference. To this aim, organisers shall assign this task to a dedicated person who will provide the first draft of the final Conference report 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.**
- EURORDIS provides a **template report** for the EUROPLAN National conferences which can be found on its website. This template must be used by each conference organiser to ensure consistency across all participating countries.
- The final draft of the Conference report could be handed in to EURORDIS either in the Conference language or in English. In the first case, EURORDIS will make sure that the final report is translated into English and the Advisor will validate the Report after translation.

Advertising outcomes of the Conference

- Conference organisers are encouraged to advertise the outcomes of the EUROPLAN National Conference on their website, and any other media support.
- EURORDIS shall upload on its website the Report of each EUROPLAN National Conference as it already did for the first 15 EUROPLAN National Conferences.

Annexe I

EUROPLAN
European Project for Rare Diseases National Plans Development

Polish EUROPLAN Project Conference

Kraków, 22.10.2010

EURORDIS
Rare Diseases Europe

Uniwersytet Jagielloński, Collegium Medicum

ul. św. Anny 12, 31-008 Kraków

Steering Committee:

Prof. dr hab. Wojciech Cichy, Prof. dr hab. Tomasz Grodzicki,

Mirosław Zieliński, lek. med. Marcin Mikoś, Paweł Wójtowicz

PLAN

10:00 - 10:30	Opening of the conference
10:30 – 11:00	**Plenary I** EUROPLAN Project - introduction
11:00 - 12:30	**Panel I**: Methodology, Governance, Monitoring and Sustainability of a National Plan *Chair: Mirosław Zieliński*
12:30 – 13:00	Coffee break
13:00 - 14:30	**(two conference halls, parallel sessions)** **Panel II**: Adequate Definition, Codification and Inventorying of Rare Diseases including Information and Training *Chair: Prof. Jolanta Sykut-Cegielska, MD, PhD* **Panel III:** Clinical and Basic Research in Rare Diseases *Chair: Prof. Anna Tylki-Szymańska,MD, PhD*
14:30 - 15:30	Lunch break
15:30 – 17:00	**(two conference halls, parallel sessions)** **Panel IV:** Standards of Care, Centers of Expertise and Orphan Drugs *Chair: Dr Jacek Graliński, MD* **Panel V:** Patient Empowerment and Gathering Expertise at the EU Level *Chair: Paweł Wójtowicz*
17:00 - 18:00	**Plenary II** Conclusions from panel discussions Closing of the conference

Annexe II

Europlan UK Conference

16th November 2010
Nowgen Centre, 29 Grafton Street, Manchester,
M13 9WU

AGENDA

Morning Session	
9.30 – 10.00	Registration and Welcome Coffee
	Plenary Session 1
10.00 – 10.30	Welcome and Introduction to the European Commission's Communication on Rare Disease and the EU Council Recommendation "Opportunity for developing a national strategy for rare disease in the UK" Alastair Kent, Chair of Rare Disease UK & Director of Genetic Alliance UK
10.30 – 11.00	The Europlan Project and developing national strategies for rare diseases Dr Edmund Jessop, National Commissioning Group, Department of Health.
11.00 – 11.15	**Tea and coffee break**
	Workshop/Breakout Session 1
11.15 – 12.45	Governance of a UK Strategy Chair: Alastair Kent, Chair of Rare Disease UK Rapporter: Stephen Nutt, Rare Disease UK
	Definition, codification and inventorying of rare disease strategy (information and training) Chair: Dr Mark Taylor, Birmingham Children's Hospital Rapporter: Lauren Limb, Rare Disease UK
	Standards of Care / Centres of expertise (orphan drugs and provision of treatment) Chair: Professor Kate Bushby, Treat NMD Rapporter: Melissa Hillier, Rare Disease UK & Genetic Alliance UK
12.45 – 2.00	**Lunch**
Afternoon Session	
	Workshop/Breakout Session 2
2.00 – 3.30	Research Chair: Dr Hilary Burton, PHG Foundation Rapporter: Lauren Limb, Rare Disease UK
	Patient Empowerment Chair: Lesley Greene, CLIMB & Eurordis and Andrew Wilson Webb, Rarer Cancers Forum Rapporter: Stephen Nutt, Rare Disease UK
	Plenary Session 2
3.30 – 4.00	Report from breakout sessions Chair: Alastair Kent, Chair of Rare Disease UK & Director of Genetic Alliance UK Chair and/or Rapporter: feedback on each workshop
4.00 – 4.30	Discussion and feedback
4.30	Tea and close

Annexe III

EUROPLAN NATIONAL GREEK CONFERENCE

Organised by PESPA, Greek Alliance for Rare Diseases

FRIDAY 26 November 2010

14:00	Registration
14:45	Coffee
14:45-15:00	Welcome – opening session
15:00-16:30	Parallel Working Groups

Working Group: 1) Methodology and administration for the National Plan- Strategy

Working Group: 2) Definition codification and inventorying of Rare Diseases

Working Group: 3) Research on Rare Diseases- Gathering the expertise on Rare Diseases at European level

Orphan Drugs

Working Group: 4) Evaluation of level of care for Rare Diseases – Centers of Expertise - European Reference Networks for Rare Diseases

Working Group: 5) Gathering Expertise on Rare Diseases at European level

- Empowerment of Patients organization
- Specialised services
- Sustainability

16:30 –17:00	Coffee break
17:00 – 19:00	Working Groups continue their session

Saturday 27 November. 2010

09:30	Coffee
10:00 – 11:30	Working Groups continue their session
11:30 – 12:00	Coffee break
12:30 –14:00	Summing up and conclusion

Working Group 1:

Chairing	A. Pantazopoulou, E.Tzala, B. Matsika
Coordinator	D. Synodinos, P. Alexandropoulou

Working Group 2:

Chairing	M. Kanavakis, M Skouroliakou, D. Sotiris, G. Voutsinas
Coordinator	G. Voutsinas, M. Traka

Working Group 3:

Chairing	A. Dretta, E. Garviel, K. Frouzis, A. Kypreos, A. Moraiti, G. Georgiadou, N. Karapanos, D. Yannoukakos
Coordinator	D. Yannoukakos, S. Gikas

Working group 4:

Chairing	S. Youroukos, E. Papadopoulou-Alataki, A Papayiannopoulou, J. Traeger-Synodinos
Coordinator	J.Traeger-Synodinos, A. Gliati

Working Group 5:

Chairing	M. Lambrou, I. Tassopoulos, Th. Stavrou, D. Delga A. Georganti
Coordinator	M. Lambrou, V. Biliou

The Greek Alliance for Rare Diseases-PESPA is organising the meeting for EUROPLAN on Friday the 26th November 2010 and Saturday the 27th November 2010.

The meeting will take place at the Eugenides Foundation, Syngrou Ave. Athens.

- PESPA has ensured the participation of all major STAKEHOLDERS, including representatives of the Greek Ministry of Health, the Greek Ministry of Labor, Greek Pharmaceutical companies, patients and patients associations, health professionals, academia, researchers, industry and other stakeholders.

Publicity prior to Conference

- In the meantime, pamphlets and posters have been distributed informing about the meeting, TV and Radio Spots by PESPA have been shown on the TV channels as well on Radio Stations in order to give the EUROPLAN Meeting more publicity throughout Greece.