

## **Report**

### **4 August 2005/Genoa Meeting Unit 6 Education (Professionals/Patients groups)**

MEETING Nadia/Domenico

- File of ESHG courses to be sent to Olivia by Domenico
- Structure of the material on the web and new proposals: titles + description + links for the annotation of the education centers or projects
- Selection of the national centers of education and online databases
- Elements of the Unit (Professionals):
  1. Educational courses data base
  2. EU national Professionals Societies
  3. EU National Health Committees
  4. National Genetics Educational Centers and . Education Units of international genetics societies
  5. Online educational materials
  6. Documents: guidelines and core competencies on genetics
  - 7 Experts' Panel

UNIT MEETING (Domenico, Nadia, Celine, Alastair, Olivia, David)

#### **1. Discussion of Celine's work:**

- Answers to the questionnaire sent by Celine to some Genetics laboratories.
- Erfocentrum NI and DISCERN mentioned as good example of online data base and resources
- Collection of evaluation tools
- Experiences in meetings at Dutch, Belgian UK centers
- 2. Discussion on meeting of 10/11 December in Leuven:
  - Presentation of material collected
  - Request of opinion from experts
  - Separate discussion groups professionals and patients' support groups
  - Final consensus conclusions and future programmes for the work
- 3. WEB editorial Committee duties: web revision, newsletters, online questionnaires

#### **4. Discussion of Nadia's work:**

- Summary of material on the web site Eurogentest
- Proposal of new files and organization of the web site ( see specifical annex Discussion with Olivia and David ) to solve some relevant problems like the collection of big files of courses, practical ways to access to the data of the database of societies etc..
- Network of national bodies : professionals' societies and health Committees
- guidelines can appear in the web site as links of web site
- Put also reports projects or research and policy statements
- 5. Meeting in Bruxelles , 12 /9/2005 : Chairs of Human Genetics Societies

6. Preparation of common background paper for November to be sent to the professionals to have comments

7. Meeting of December in Leuven:

-Presentation of material collected

-Request of opinion from experts

-Separate discussion groups for professionals and patients

## 5 August 2005

Meeting at Galliera Hospital ( Unit 6 + Nagley, Renza, Matteo from Patients support Italian groups + Franca , head of Genetics + Francesca of Genetics Dep. of Galliera Hospital of Genoa)

Participants' data:

-Nadia Ceratto, GIG 0032 472 300129 [nadia.ceratto@skynet.be](mailto:nadia.ceratto@skynet.be) Bruxelles

-Domenico Coviello Fondazione-IRCCS 00393355793885 [coviello@unige.it](mailto:coviello@unige.it) Milan  
Ospedale Maggiore Policlinico, Mangiagalli e Regina Elena

-David Bishop , waypointsystems 0044 7887552582 [d.bishop@waypointsystems.co.uk](mailto:d.bishop@waypointsystems.co.uk)

-Olivia Willcocks ,waypointsystems 00447717452486 Shrewsbury

[o.willcocks@waypointsystems.co.uk](mailto:o.willcocks@waypointsystems.co.uk)

-Alastair Kent , GIG and EGAN 00442077043141 [alastair@gig.org.uk](mailto:alastair@gig.org.uk) London

-Celine Lewis GIG 00442077043141 [celine@gig.org.uk](mailto:celine@gig.org.uk) London

-Nagley Losa aidweb 00393401461378 [nagley@aidweb.org](mailto:nagley@aidweb.org) Milan

-Renza Rabon Galluppi, Uniamo 0039 3385893898 [segreteria@uniamo.org](mailto:segreteria@uniamo.org) Venice

-Matteo Scarpellini, Lions 00393356234341 [lions@scarpellini.com](mailto:lions@scarpellini.com) Bergamo

-Franca Dagna Bricarelli , Galliera Hospital 00393281503310 [dagna@galliera.it](mailto:dagna@galliera.it) Genoa

1. Presentation of Eurogentest project ( Domenico+ Alastair)

2. Separation in 2 groups to discuss different topics : patients, services etc in Galliera Hospital ed in Italy (Celine, Franca, Nagley, Renza) and common background and programme for the Meeting at Leuven ( rest of people).

## COMMON BACKGROUND

Contents

1. Introduction

-professionals communication quality

-responsibilities in genetics education at different levels : state, bodies, institutes..etc

-quality services delivery at clinic and laboratory levels

2. Professionals training: education at different levels

3. Recognition of Medical Genetics as EU Specialty and at national levels in EU

Countries : state of art and future goals

4. Minimal education , core competencies

5. Methodology to obtain information about educational material e links to the web sites
6. Expectations of different categories of professionals and of patients
7. Roles of health-care providers and health national committees

Meeting in Leuven 10/11 December 2005 (presented by Alastair)

Alastair will send the programme and the list of Experts' Panel by email to us.

Notes:

1. Separation of professionals' and patients' support groups sessions : discussion of results of the surveys.
2. Peter and Heather talks
3. General discussion
4. Separation of the groups to elaborate the future goals and work plan.

TIMELINE

1. End of September: common background
2. End October : advanced version to be sent to the experts
3. First week of November : c.b sent

**WEB SITE STRUCTURE PROFESSIONALS** (Nadia + Olivia + David discussion)

1. Olivia will be create a structure to contain different boxes, trails ..etc to structure the material on the web and will send to us to choose one of them.
2. File ETHICS : will be complete with the web links sending them by Nadia to Olivia
3. Deletion of EU educational initiatives sect. A e B files
4. Creation of a new file : Educational programmes divided in programmes and courses. The courses will sorted by keywords in a data base ( see the annex of David's web site comments)
5. Add the section Meetings with 2 sections: public part and professionals part
6. Heath Committees will stay
7. Genetic Organization data base will stay and updating sending by Nadia to Olivia group of news to add/to change the information available on the web.
8. Add Documents section with different categories:
  - guidelines
  - research projects reports
  - policy statements
  - workshop reports
  - discussion documents
9. Add Educational Units and Centers divided in Europe an Other countries

## Website (Professionals) Comments of David

### Homepage

#### Courses Database

- Course Name
- Host Institution
  - Address
- Exit Award / CPD Points
- Duration
- Mode of Study (Full time, part time, distance learning)
- Code of Target (12345???)
- Current/Archive
- Sunset clause
- Type of Course
- Start Date
- Applications By
- Rolling start date
- Automatic Email Notification to course organiser when course finishes
- Number of Places
- Course Status (open, full)
- Course is about to drop to close list, what do you want to do about it.
- A collection of choice boxes to click to choose what to do next with course.
- Searchable

