



www.eshg.org
**European Society
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**Email to the
Presidents of National European
Human Genetics Societies**

November 18, 2009

Subject: Letter to the Presidents of National Human Genetics Societies on EU-wide recognition of our specialty: update and next steps

Dear All,

first and foremost let me sincerely thank you for your support (see your ESHG2009 petition- <https://www.eshg.org/index.php?id=111>) and your relentless individual lobbying of your national representatives from the „Recognition Committee (or RC)“ of the European Commission´s - DG Internal Market and Services. This committee is in charge of amending Directive 2005/36 with our specialty and follows the EU Council „Qualified Vote“ procedure - http://en.wikipedia.org/wiki/Voting_in_the_Council_of_the_European_Union. Essentially this committee represents Member State „interests“ and its national representatives provide an „official position“ of a given country on EU-wide recognition of any given specialty (from architects, through lawyers down to medical specialties). This Committee should in theory liaise with national professional bodies (such as clinical / medical genetics societies) and get their opinion on EU-wide recognition of a specialty and thereby its inclusion into the list of specialties in Directive 2005/36. However, given the broad scope of the RC a more proactive approach from your side gets things forward.

Without going much into detail I would like to brief you as to what is the:

A/ Current status

1/ thanks to your help we have provided the EC via national RC representatives with 1/ endorsement letters from national societies, 2/ national legal dossiers which officially recognise our specialty in a given EU Member State, 3/ duration of postgraduate training and 4/ national postgraduate curricula for training in our specialty. An overview, including translation of curricula into English (by EC services) is presented at the ESHG website - <https://www.eshg.org/index.php?id=111>. Please check your national data and where applicable send the missing info – such as postgraduate curricula to me and in copy to Mr. Jerome del Picchia at WMA (eo@medacad.org) in order to update the ESHG website and the EC

2/ thanks to the activities of prof. John Burn and prof. Arnold Munnich – the French Ministry of Health officially requested in March 2009 that DG Internal Market and Services via its RC starts deliberations leading to the formal amendment of Directive 2005/36 with clinical / medical genetics, thereby in the end leading to EU-wide recognition of our specialty.

3/ the subsequent Czech EU Council presidency (www.eu2009.cz) followed upon this initiative and you were very kind to provide quickly all requested documents (Point A1) and through the adoption of the EU Council Recommendation on the EU Action in the field of rare diseases (80% are of genetic origin) provide a justification for „crossborder provision of expertise“ in our field - <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF> (Recital 15)



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4/ during the last several years prof. Kristoffersson and Dr. Kingston have worked hard at UEMS (www.uems.org) which led to the establishment of the consensus postgraduate curriculum for clinical / medical genetics - <https://www.eshg.org/index.php?id=111>. This document importantly states the minimum 4 year duration of such training

5/ On October 22 I have been in Brussels at the autumn meeting of the RC where I was able thanks to the kind help of Ms. Lucia Slobodova (Czech representative at the RC) present the status of the field and show that recognition of our specialty has received unanimous support from the EU professional societies, that we complied with the RC request and submitted all documents requested (Point 1A). Importantly, we also demonstrated that there are no „aberrant curricula“ which could jeopardise crossborder provision of expertise within the EU and they all comply with the UEMS-based consensus (see powerpoint attachment)

6/ At this meeting the EC carried out an informal voting procedure, whereby individual RC national representatives were asked to provide their position on a/ whether they approve the „amendment“ and b/ whether they agree with the minimal 4 years duration of postgraduate training or would like to have 5 years instead (the extra year is mostly due to „clinical elective“). The status of this exercise is summarised in the attached excel spreadsheet. As you can see the response was positive and we are „almost there“!

B/ Next steps

1/ Currently the EC officially asked RC representatives to provide a written position supporting their preliminary approval at the October 22 meeting. This is particularly important in instances where RC committee members abstained, either because their country does not have the specialty (BE, CY, EL, LUX, ISL), or where they only conditionally approved (IT, SE – taking time to consult the duration of postgraduate training) or for other unknown reasons abstained (EE, HU, MT, PO, RO, SI). Note: EEA countries (eg. NO, CH, ISL) are only present as observers and are non-voting RC members. In last several days I have individually been in contact with many of you and asked you to recontact your national representatives at the RC and brief them on the situation in your country where RC members have not presented their position.

2/ Now all is in the hands of national RC representatives, whom you contacted previously, and generally no action is needed from your side except for those of you „whose“ national RC representatives abstained at the October 22 meeting) – the main issue which they are asked to provide is

a/ whether they approve the move and b/ whether they agree with the consensus 4 year duration of postgraduate training in clinical / medical genetics (see email below from the EC to the RC)

Finally, if everything goes well the March 2010 RC meeting could be set by the EC as „voting“ and our goal would have been administratively achieved. The Directive 2005/36 itself is scheduled for Amendment in 2012 and the list of specialties to be included (and which passed the above specified RC procedure) will be voted upon by the members of the European Parliament.

Best regards and let us hope for the best !

Milan Macek, Jr.
President-elect of the ESHG