EU Council Recommendation on European Action in the field of rare diseases: its relation to EU27 recognition of clinical / medical genetics

Milan Macek Jr.

Institute of Biology and Medical Genetics
Charles University Prague and Faculty Hospital Motol

5th Meeting, National Human Genetics Societies (NHGSs)
Vienna, 2009

Definition of a rare disease

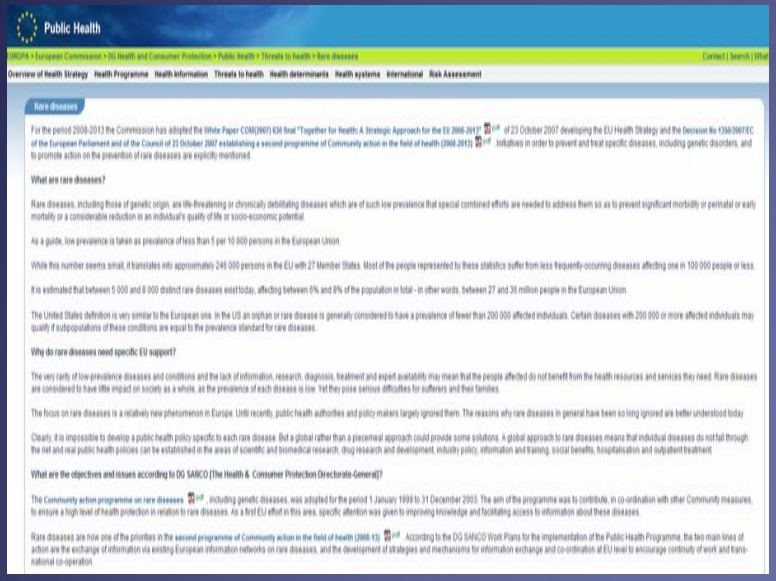
A condition affecting less than 1 person in 2000 (5 per 10 000)
i.e. in line with the regulation of the European Medicine Agency
(www.emea.europa.eu) -> orphan medicinal products with special status

EU Commission on Public Helath defines a rare diseas as
„life threatenining or chronically debilitating disease, which are
of such low prevalence that a special combined effort is needed
to address them (CE141/2000)“

It is estimated that up to 8000 distinct rare diseases exist today:
their extreme heterogeneity, lack of proper coding (only 250 are
listed in ICD 10) require a Community wide initiative (together with US)

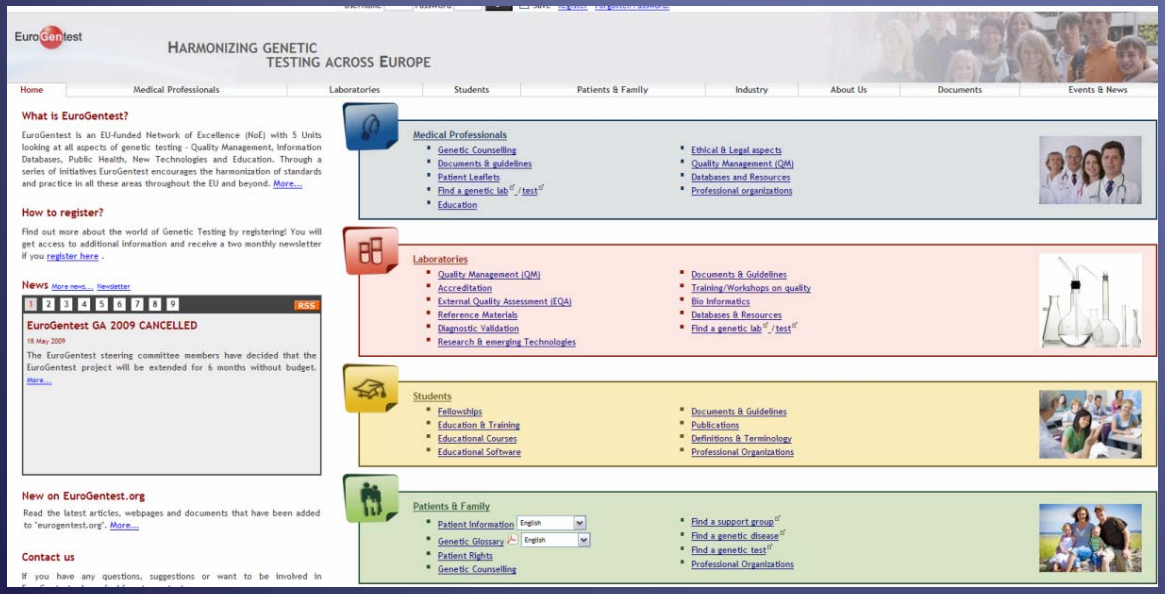
Since over 80% of rare diseases have a defined genetic origin
clinical / medical genetics play a crucial role in their early diagnosis
and management

Information portals



http://ec.europa.eu/health/ph_threats/non_com/rare_diseases_en.htm

http://www.orpha.net



http://www.eurogentest.org

Despite being a crucial specialty for rare diseases our specialty was NOT included in Directive 2005/36/EC

DIRECTIVE 2005/36/EC OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL

of 7 September 2005

on the recognition of professional qualifications

(Text with EEA relevance)

THE EUROPEAN PARLIAMENT AND THE COUNCIL OF THE EUROPEAN UNION,

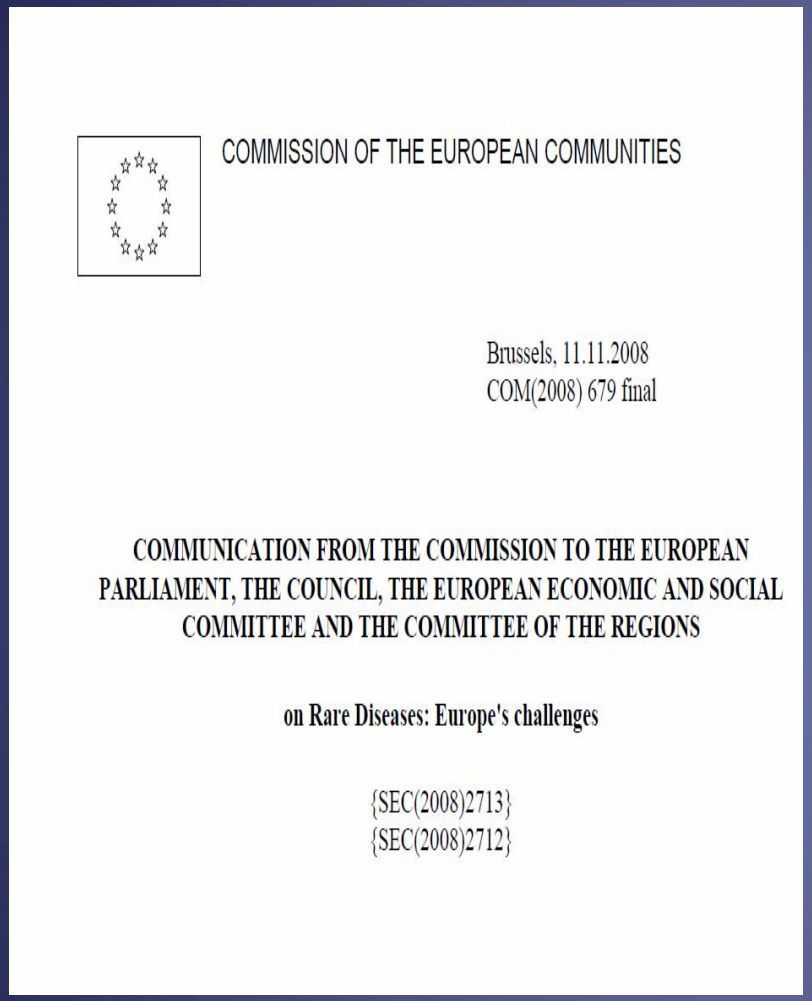
Having regard to the Treaty establishing the European Community, and in particular Article 40, Article 47(1), the first and third sentences of Article 47(2), and Article 55 thereof,

Having regard to the proposal from the Commission ([1]),

(3) The guarantee conferred by this Directive on persons having acquired their professional qualifications in a Member State to have access to the same profession and pursue it in another Member State with the same rights as nationals is without prejudice to compliance by the migrant professional with any non-discriminatory conditions of pursuit which might be laid down by the latter Member State, provided that these are objectively justified and proportionate.

Acknowledging specialisation at a EU-wide level for CROSSBORDER provision of MEDICAL CARE

Main European documents for RDs



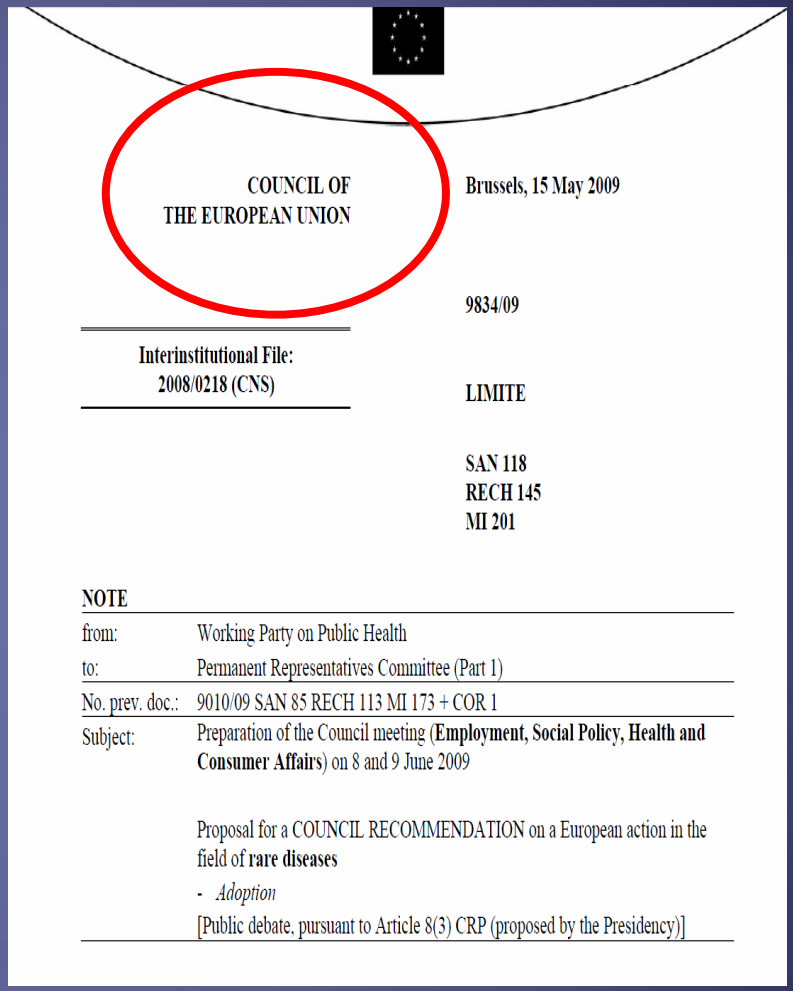
COMMISSION OF THE EUROPEAN COMMUNITIES

Brussels, 11.11.2008
COM(2008) 679 final

COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS

on Rare Diseases: Europe's challenges

{SEC(2008)2713}
{SEC(2008)2712}



COUNCIL OF
THE EUROPEAN UNION

Brussels, 15 May 2009

9834/09

Interinstitutional File:
2008/0218 (CNS)

LIMITE

SAN 118
RECH 145
MI 201

NOTE

from:	Working Party on Public Health
to:	Permanent Representatives Committee (Part 1)
No. prev. doc.:	9010/09 SAN 85 RECH 113 MI 173 + COR 1
Subject:	Preparation of the Council meeting (**Employment, Social Policy, Health and Consumer Affairs**) on 8 and 9 June 2009
	Proposal for a COUNCIL RECOMMENDATION on a European action in the field of **rare diseases**
	- *Adoption*
	[Public debate, pursuant to Article 8(3) CRP (proposed by the Presidency)]

http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf
http://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf
www.rtdf.org

EU2009.CZ

Rare diseases are one of the priorities of the CZ EU Council Presidency

(3) The Community Action Programme on Rare Diseases, including genetic diseases, was adopted for the period 1 January 1999 to 31 December 2003[6]. This programme arbitrarily defined the prevalence for a rare disease as affecting no more than 5 per 10 000 persons in the EU. A more refined definition, taking into account both prevalence in the general population (at EU and/or national levels) and at birth prevalence based on continuous catalogues and/or scientific review, will be developed using the Community Health Programme resources.

(4) Regulation (EC) No 141/2000 of the European Parliament and of the Council of 16 December 1999 on orphan medicinal products provides that a medicinal product shall be designated as an "orphan medicinal product" when intended for the diagnosis, prevention or treatment of a life-threatening or chronically debilitating condition affecting not more than 5 in 10 000 persons in the Community when the application is made.

(5) Currently it is estimated that between 5 000 and 8 000 distinct rare diseases exist, affecting between 6 % and 8 % of the population in their lifetime. In other words, although rare diseases are characterized by low prevalence for each of them, the total number of people affected ranges[7] between 27 and 36 million people in the EU. Most of them suffer from extremely rare diseases affecting one in 100 000 individuals or less. These patients and their families are particularly isolated and vulnerable.

(6) Rare diseases differ widely in severity and in expression. Persons suffering from rare diseases have a significantly lower life expectancy. Many such diseases are complex degenerative and chronically debilitating, whilst others are compatible with normal life if diagnosed in time and managed and/or treated properly. Several disabilities often co-exist, with many functional consequences upon the affected. Such disabilities enhance the feeling of

Komentář [M3]: Místo "A" je lepší dát konkrétní "The"
Naformátováno: zvýrazněné
Komentář [MM4]: Tím se zdůrazňuje skutečnost, že je to "umělá definice"= arbitrary, kterou bude nutno s vývojem oboru aktualizovat, ostatně takjak požadují Amendments 2 a 3 + ECOSOC
Komentář [M5]: Sjednotil jsem psaní EU v dokumentu, někde to bylo rozepsané, někde ve zkratce, takže je lepší nechat zkratku
Komentář [MM6]: General population je epidemiologický technický termín, který zpřesňuje slovo « prevalence », která může mít spoustu typů a podob ; u RD je to populační prevalence
Naformátováno: zvýrazněné
Komentář [M7]: And/or - The legal phrase "and/or," indicating that you can either choose between two alternatives or choose both of them, has proved irresistible in other contexts and is now widely acceptable - je to tedy lepší anglická formulace
Komentář [MM8]: Toto odráží správný požadavek, že v některých populacích díky jejich genetickým rozdílům některé choroby jsou časté a jiné nikoli a liší se to mezi jednotlivými členskými zeměmi EU – Amendment 19 + ECOSOC
Komentář [M9]: Oboji se vzájemně nevylučuje a spíše doplňuje – and/or
Naformátováno: zvýrazněné
Naformátováno: Barva písma: Červená,zvýrazněné
Komentář [MM10]: Toto je EMEA definice a je to proto OK
Komentář [MM11]: Současný stav věci "Current" s ohledem na nutnost neustále aktualizace jak požadují Amendments 2,3
Komentář [M12]: Nahrazeno currently
Komentář [MM13]: Toto je formulace z lékařských učebnic a je to tedy technicky termín – "course of their lives" se nepoužívá
Naformátováno: Písmo: není Tučné
Komentář [MM14]: To je v pořádku a jedná se spíše o formulační záležitost.
Komentář [M15]: Sjednocení na zkratku
Komentář [MM16]: Zde jsem opět použil odborné termíny, které jsou technicky přesné
Naformátováno: zvýrazněné
Naformátováno: Angličtina (Velká Británie)

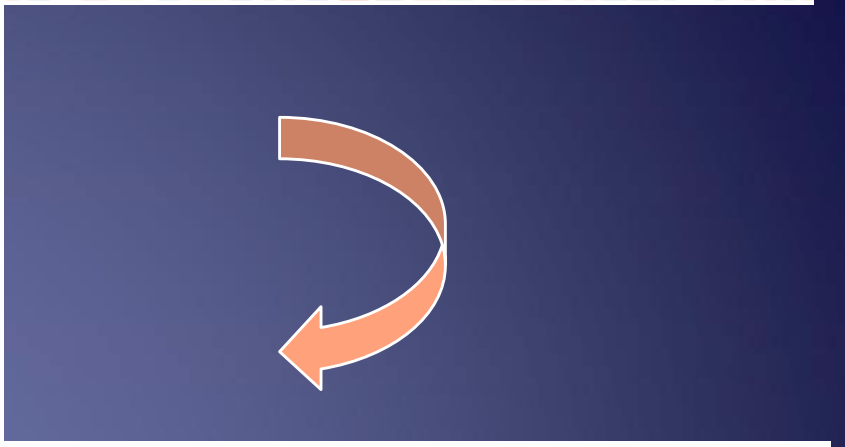
Employment, Social Policy, Health and Consumer Affairs Council (EPSCO)

Date: 8.6.2009 – 9.6.2009
Venue: Luxemburg
Category: Council of Ministers
Theme: Employment, Soc. Pol., Health and Cons. Affairs

Top of Page ↑ | Back to list ← | New search | Add to my calendar → 1

Helena Holpuchová, Kristina Masala, Iva Truellová, Klaudie Faltysová, Lenka Kostelecká, Stanislava Pánová, Lucia Slobodová

(15) In December 2006 an expert group of the European Union Rare Diseases Task Force issued a report "Contribution to policy shaping: For a European collaboration on health services and medical care in the field of rare diseases"[10] to the High Level Group on Health Services and Medical Care. The expert group report outlines, inter alia, the importance of identifying centres of expertise and the roles that such centres should fulfil. It is also agreed that, in principle and where possible, expertise should travel rather than patients themselves. Some measures called for in the report are included in this Recommendation.



5. Gathering the expertise on rare diseases at European level

gather national expertise on rare diseases and support the pooling of that expertise with European counterparts in order to support:

(1) sharing of best practices on diagnostic tools and medical care as well as education and social care in the field of rare diseases;

(2) adequate teaching and training for all health professionals to make them aware of the existence of these diseases and of resources available for their care;

(3) development of medical training in fields relevant to the diagnosis and management of rare diseases (e.g. genetics, immunology, neurology, oncology, paediatrics);

(4) development of European guidelines on diagnostic tests, population screening while respecting national decisions and competences;

(5) sharing Member States' assessment reports on the therapeutic or clinical added value of orphan drugs at Community level where the relevant knowledge and expertise is gathered, in order to minimise delays in access to orphan drugs for rare disease patients.

http://ec.europa.eu/health/ph_threats/non_com/rare_10_en.htm

ΕΛΛΑΔΙΚΗ ΠΡΟΕΔΡΙΑ
ΕΥΡΩΠΑΪΚΗ ΕΝΩΣΗ
FRANCIA ELNÖKSÉG
EURÓPAI UNIÓ
UACHTARÁNACHT NA FRAINCE
AN ŁAONTAS EORPACH
PRESIDENZA FRANCESE
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+

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John BURN

Arnold MUNNICH

Roselyne BACHELOT

- NARQUIN

Breakfast meeting with the French Minister of Health; XI/2008

French request to the EC

DG Internal Market and Services

Inclusion of Specialty under Annex V.

EUROPEAN COMMISSION
Internal Market and Services DG

KNOWLEDGE-BASED ECONOMY
Regulated professions

Brussels, 23 March 2009
MARKT D/57617/2009-FR/EN

DIRECTIVE 2005/36/EC
COMMITTEE
FOR THE RECOGNITION OF PROFESSIONAL QUALIFICATIONS

French request for inclusion of specialty of Medical Genetics under Annex V

NOTE FROM THE FRENCH AUTHORITIES
FOR THE COMMISSION OF THE EUROPEAN COMMUNITIES

Concerning the specialty of Medical Genetics, the French authorities wish to address the question of its existence and of its content in the other countries of the European Union in the Committee of Directive 2005/36/EC in view of its inclusion, if necessary, in the list of those specialties which can benefit from mutual recognition, insofar as at least 2/5 of the Member States would already recognise this specialty. In France this is a speciality sanctioned by a specialised diploma (diplôme d'études spécialisées – DES), issued by the universities. You will find in annex a sheet recapitulating the activities concerned and the duration of training.

Multidisciplinary Joint Committee - Clinical Genetics (MJC)

Ulf Kristoffersson

www.uems.net

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES
EUROPEAN UNION OF MEDICAL SPECIALISTS

Kroonlaan 20 Avenue de la Couronne
B-1050 - BRUSSELS
www.uems.net

tel: +32-2-649.51.64
fax: +32-2-640.37.30
uems@skynet.be

UEMS 2009 / 15

Description of Clinical Genetics as a medical specialty in EU
Aims and objectives for specialist training

Endorsed by: *The European Society of Human Genetics board and membership (2007)*
The UEMS Multidisciplinary Joint Committee for Clinical Genetics (Jan 21, 2009)
The UEMS Specialist Sections & European Boards (Feb 21, 2009)

Adopted by: *The UEMS Council (April 25, 2009)*

Specialty Profile

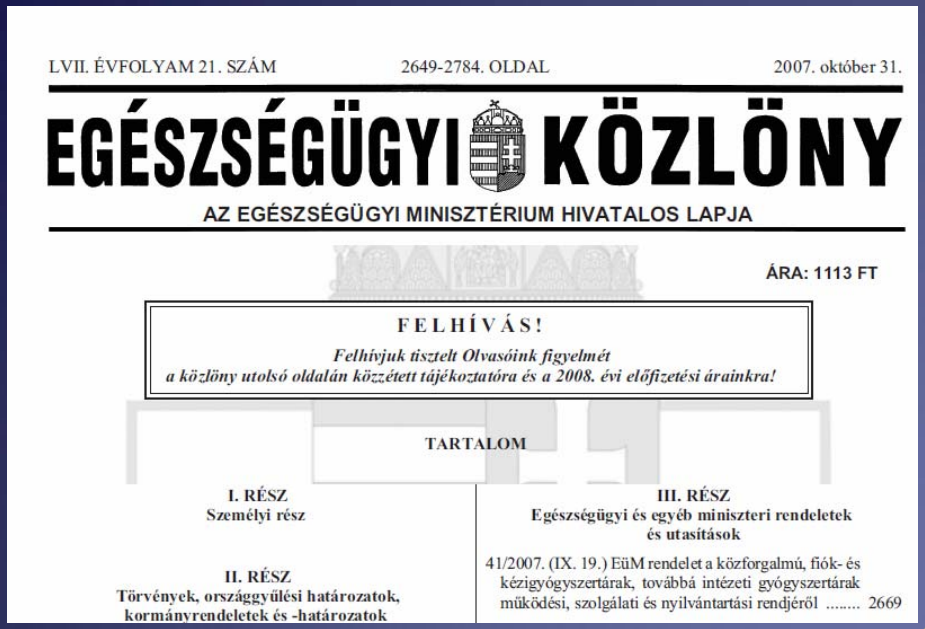
Clinical Genetics describes the medical elements of Genetics Services provided to individuals and families (and sometimes populations). Other components include laboratory genetics (cytogenetics, molecular genetics, and biochemical genetics), genetic counselling and academic genetics. The core activities of a genetic service can be defined as 'integrated clinical and laboratory services, provided for those with/concerned about a disorder with a significant genetic component (both inherited and sporadic). Due to the sharing of genes among family members, the whole family, not only the individual, represents the core patient in clinical/medical genetics.

This document relates to medically qualified individuals intending to train in the specialty of Clinical/Medical Genetics. It recognises that there may be overlaps with training programmes for other genetic professionals (scientists and counsellors) and that there may be opportunities for joint training for periods of the course.

Entry criteria

This may vary from country to country but would generally include a specified period of general medical training to include adult +/- paediatric medicine prior to commencing specialty training in Clinical Genetics, "internship". Some countries may have a minimum period of training to be undertaken before specialisation.

President: Dr. Zlatko Fras
Treasurer: Dr. Giorgio Berchicci
Secretary General: Dr. Bernard Maillet
Liaison Officer: Dr. Gerd Hofmann



LVII. ÉVFOLYAM 21. SZÁM 2649-2784. OLDAL 2007. október 31.

EGÉSZSÉGÜGYI KÖZLÖNY

AZ EGÉSZSÉGÜGYI MINISZTÉRIUM HIVATALOS LAPJA

ÁRA: 1113 FT

FELHÍVÁS!

Felhívjuk tisztelt Olvasóink figyelmét
a közlöny utolsó oldalán közzétett tájékoztatóra és a 2008. évi előfizetési árainkra!

TARTALOM

LATVIJAS VĒSTNESIS

LATVIJAS REPUBLIKAS OFICIĀLAIS LAIKRAKSTS

Publicēts: Latvijas Vēstnesis > 18.04.2000 136/139 (2047/2050) > Ministrijās

Labklājības ministrija

Rīkojums Nr.127 Rīgā 2000.gada 11.aprīlī

Par ārstu specialitāšu nolikumu apstiprināšanu

Izdots saskaņā ar Ārstniecības likuma 27.pantu

1. Apstiprināt:

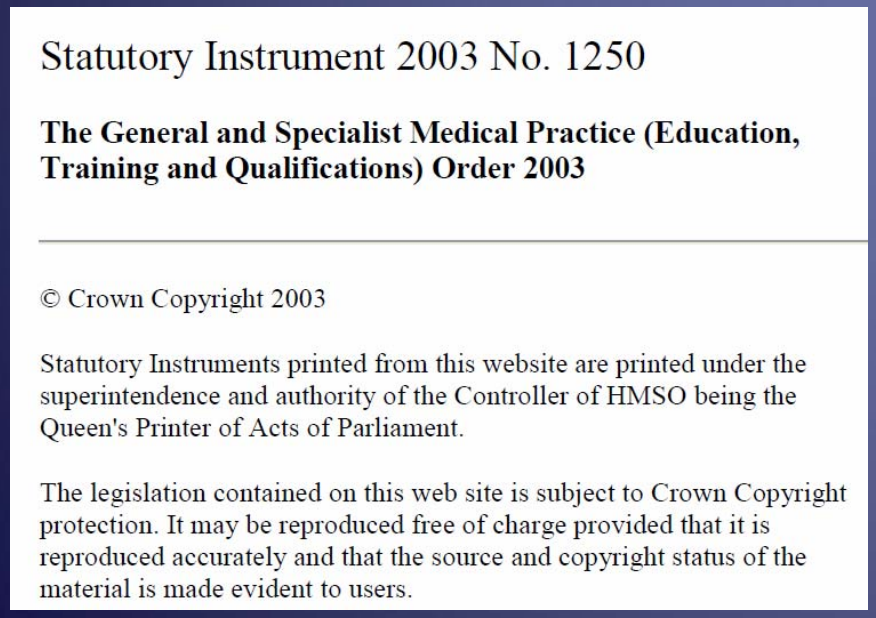
1.1. Sirds ķirurga specialitātes nolikumu;

1.2. Asinsvadu ķirurga specialitātes nolikumu;

1.3. Bērnu neirologa specialitātes nolikumu;

1.4. Mutes, sejas un žokļu ķirurga specialitātes nolikumu;

1.5. Ārsta ģenētiķa specialitātes nolikumu;



Statutory Instrument 2003 No. 1250

The General and Specialist Medical Practice (Education, Training and Qualifications) Order 2003

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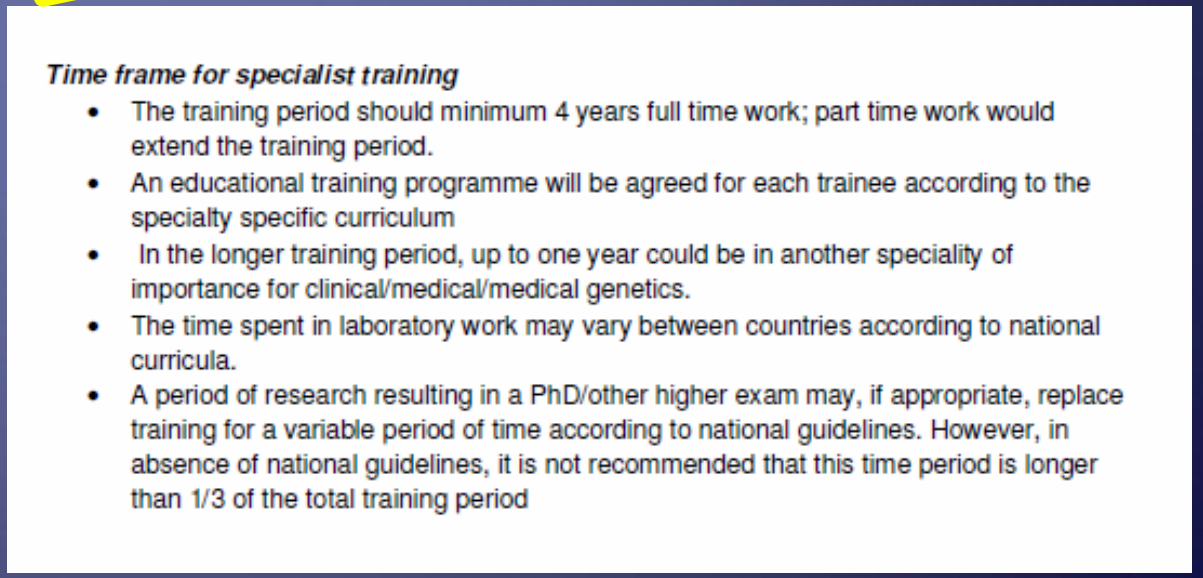
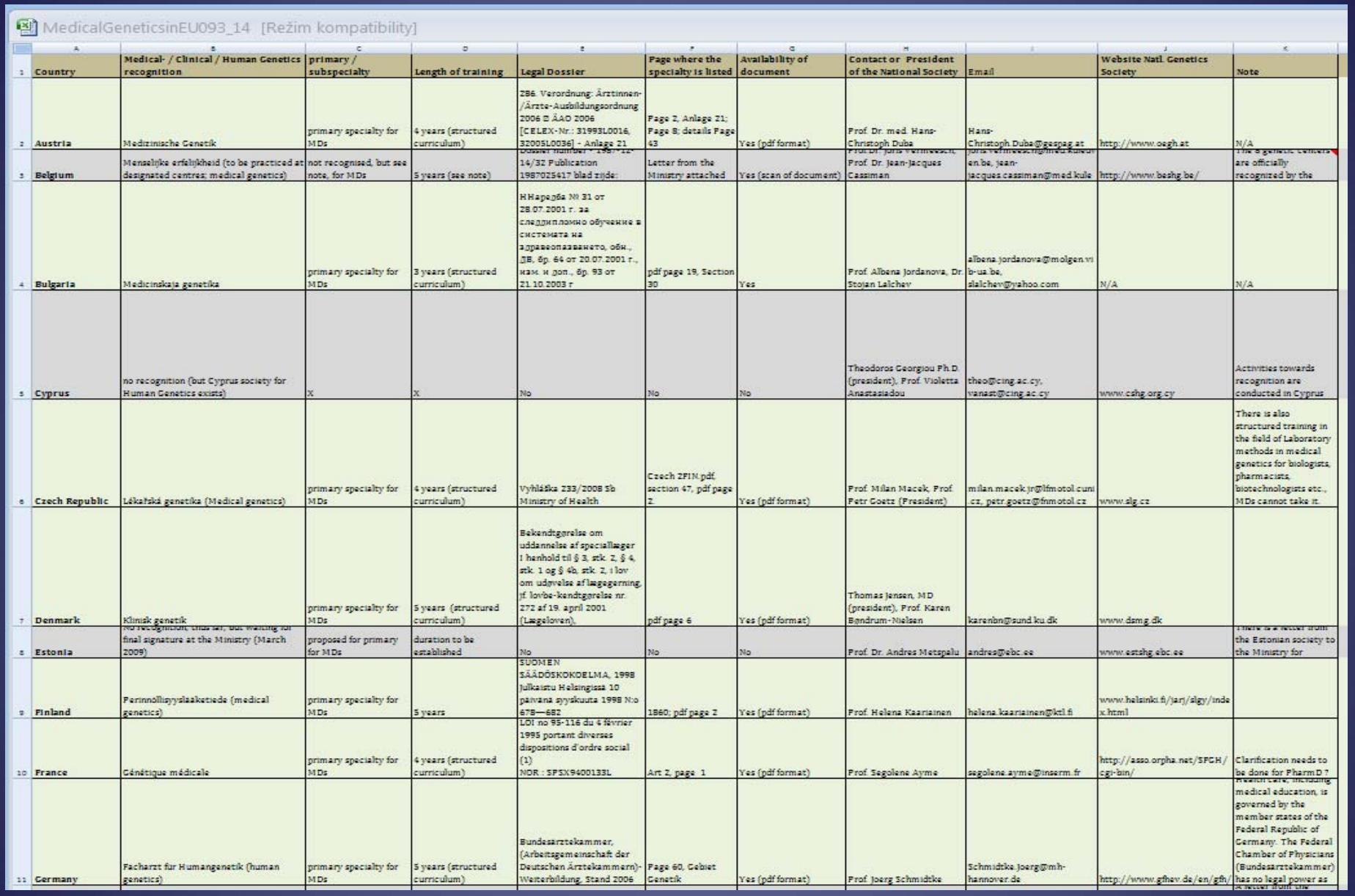


Time frame for specialist training

- The training period should minimum 4 years full time work; part time work would extend the training period.
- An educational training programme will be agreed for each trainee according to the specialty specific curriculum
- In the longer training period, up to one year could be in another speciality of importance for clinical/medical/medical genetics.
- The time spent in laboratory work may vary between countries according to national curricula.
- A period of research resulting in a PhD/other higher exam may, if appropriate, replace training for a variable period of time according to national guidelines. However, in absence of national guidelines, it is not recommended that this time period is longer than 1/3 of the total training period



MedicalGeneticsinEU093_14 [Režim kompatibility]

	Country	Medical- / Clinical / Human Genetics recognition	primary / subspecialty	Length of training	Legal Dossier	Page where the specialty is listed	Availability of document	Contact or President of the National Society	Email	Website Natl. Genetics Society	Note
2	Austria	Medizinische Genetik	primary specialty for MDs	4 years (structured curriculum)	286. Verordnung: Ärztinnen-/Ärzte-Ausbildungsordnung 2006 Ø ÄAO 2006 [CELEX-Nr.: 31993L0016, 32005L0036] - Anlage 21	Page 2, Anlage 21; Page 8; details Page 43	Yes (pdf format)	Prof. Dr. med. Hans-Christoph Duba	Hans-Christoph.Duba@gespag.at	http://www.oegh.at	N/A
3	Belgium	Menselijke erfelijkheid (to be practiced at designated centres; medical genetics)	not recognised, but see note, for MDs	5 years (see note)	Dossier number : 198.112-14/32 Publication 1987025417 blad zijde:	Letter from the Ministry attached	Yes (scan of document)	Prof. Dr. Jean-Jacques Cassiman	jean-jacques.cassiman@med.kuleuven.be, jean-jacques.cassiman@med.kule	http://www.beshg.be/	The 5 genetic centers are officially recognized by the
4	Bulgaria	Medicinskata genetika	primary specialty for MDs	3 years (structured curriculum)	ННаредба № 31 от 28.07.2001 г. за следдипломно обучение в системата на здравеопазването, обн., ДВ, бр. 64 от 20.07.2001 г., изм. и доп., бр. 93 от 21.10.2003 г	pdf page 19, Section 30	Yes	Prof. Albena Jordanova, Dr. Stojan Lalchev	albena.jordanova@molgen.vib-ua.be, slalchev@yahoo.com	N/A	N/A
5	Cyprus	no recognition (but Cyprus society for Human Genetics exists)	X	X	No	No	No	Theodoros Georgiou Ph.D. (president), Prof. Violetta Anastasiadou	theo@cing.ac.cy, vanast@cing.ac.cy	www.cshg.org.cy	Activities towards recognition are conducted in Cyprus
6	Czech Republic	Lékařská genetika (Medical genetics)	primary specialty for MDs	4 years (structured curriculum)	Vyhláška 233/2008 Sb Ministry of Health	Czech ZFIN.pdf, section 47, pdf page 2	Yes (pdf format)	Prof. Milan Macek, Prof. Petr Goetz (President)	milan.macek.jr@lfmotol.cuni.cz, petr.goetz@fnmotol.cz	www.slg.cz	There is also structured training in the field of Laboratory methods in medical genetics for biologists, pharmacists, biotechnologists etc., MDs cannot take it.
7	Denmark	Klinisk genetik	primary specialty for MDs	5 years (structured curriculum)	Bekendtgørelse om uddannelse af speciallæger I henhold til § 3, stk. 2, § 4, stk. 1 og § 4b, stk. 2, i lov om udøvelse af lægegerning, jf. lovbe-kendtgørelse nr. 272 af 19. april 2001 (Lægeloven).	pdf page 6	Yes (pdf format)	Thomas Jensen, MD (president), Prof. Karen Brøndrum-Nielsen	karenbn@sund.ku.dk	www.dsmg.dk	
8	Estonia	No recognition, this far, but waiting for final signature at the Ministry (March 2009)	proposed for primary for MDs	duration to be established	No	No	No	Prof. Dr. Andres Metspalu	andres@ebc.ee	www.eshg.ebc.ee	There is a letter from the Estonian society to the Ministry for
9	Finland	Perinnöllisyyslääketiede (medical genetics)	primary specialty for MDs	5 years	SUOMEN SÄÄDÖSKOKOELMA, 1998 Julkaistu Helsingissä 10 päivänä syyskuuta 1998 No 678—682	1860; pdf page 2	Yes (pdf format)	Prof. Helena Kaariainen	helena.kaariainen@ktl.fi	www.helsinki.fi/jarj/slgy/index.html	
10	France	Génétique médicale	primary specialty for MDs	4 years (structured curriculum)	LOI no 95-116 du 4 février 1995 portant diverses dispositions d'ordre social (1) NOR : SPSX9400133L	Art 2, page 1	Yes (pdf format)	Prof. Segolene Ayme	segolene.ayme@inserm.fr	http://asso.orpha.net/SFGH/cgi-bin/	Clarification needs to be done for PharmD ?
11	Germany	Facharzt für Humangenetik (human genetics)	primary specialty for MDs	5 years (structured curriculum)	Bundesärztekammer, (Arbeitsgemeinschaft der Deutschen Ärztekammern)- Weiterbildung, Stand 2006	Page 60, Gebiet Genetik	Yes (pdf format)	Prof. Joerg Schmidtke	Schmidtke.Joerg@mh-hannover.de	http://www.gfhev.de/en/gfh/	Health care, including medical education, is governed by the member states of the Federal Republic of Germany. The Federal Chamber of Physicians (Bundesärztekammer) has no legal power as

Primary specialty in 20/27 EU member states (9xclinical 10x medical, 1x human, 1x genetics)
Recognition process underway / applied in BE, EE, GR, CY and ES,;no recognition in LU

ORDEM DOS MÉDICOS

Conselho Directivo do
COLÉGIO DE GENÉTICA MÉDICA

Ms. Lucia Slobodová
Czech Ministry of Education and Sports
Prague, Czech Republic

20 May 2009

Dear Ms. Lucia Slobodová

This letter is to let you know that the Portuguese College of Medical Genetics, the professional organization responsible for approving and overseeing the training and education of medical geneticists in Portugal, at our national Medical Association ("Ordem dos Médicos"), fully endorses the UEMS Clinical Genetics curriculum, with the total length of 4 years, as stated in the "Description of Clinical Genetics as a medical specialty in EU: aims and objectives of specialist training", adopted on 25 April 2009.

Clinical Genetics ("Genética Médica", in Portugal) is a primary full specialty of its own right, since 1998 (before then it was only a "Competence", secondary to obtaining another previous specialty). This College was then formed in 2000, and the education and training programme was elaborated by us and officially approved and published as Portaria no. 148/2001, from 2 March, in "Diário da República" - I série-B no. 52, 1174.

Though the training period is of 5 years in our country, this does include a period of 12 months of basic clinical training (in general paediatrics, obstetrics, neonatology, neurology, internal medicine or other options). We will, thus, have no objections in accepting and recognizing the education in other European countries where the training period is at least 4 years.

The board of the Portuguese College of Medical Genetics, thus, fully supports and endorses the inclusion of Clinical Genetics ("Genética Médica") into Directive 2005/36, towards the recognition of this important specialty at the European level.

Sincerely yours,

Jorge Sequeiros, MD, PhD
Medical Geneticist
President of the College of Medical Genetics,
Portugal

EUROPEAN COMMISSION
Directorate-General for Internal Market and Services

KNOWLEDGE-BASED ECONOMY
Regulated professions

Brussels, 15.05.2009
MARKT D/56651/1/2009-EN

Group of Coordinators for the recognition of professional qualifications

Situation in Member States for specialty of Medical Genetics

Information provided by CZ

Deadline May 29, 2009

Meeting of 22 June 2009

Amendment planned for 2012

Guidelines for Quality Assurance in Molecular Genetic Testing

http://www.oecd.org/dataoecd/43/6/38839788.pdf

that ensures their competence.

Laboratory specialty

E.3 Existing specialist education and training programmes relevant to molecular genetic testing that meet recognised standards should be formally adopted by governments, regulatory and/or professional bodies.

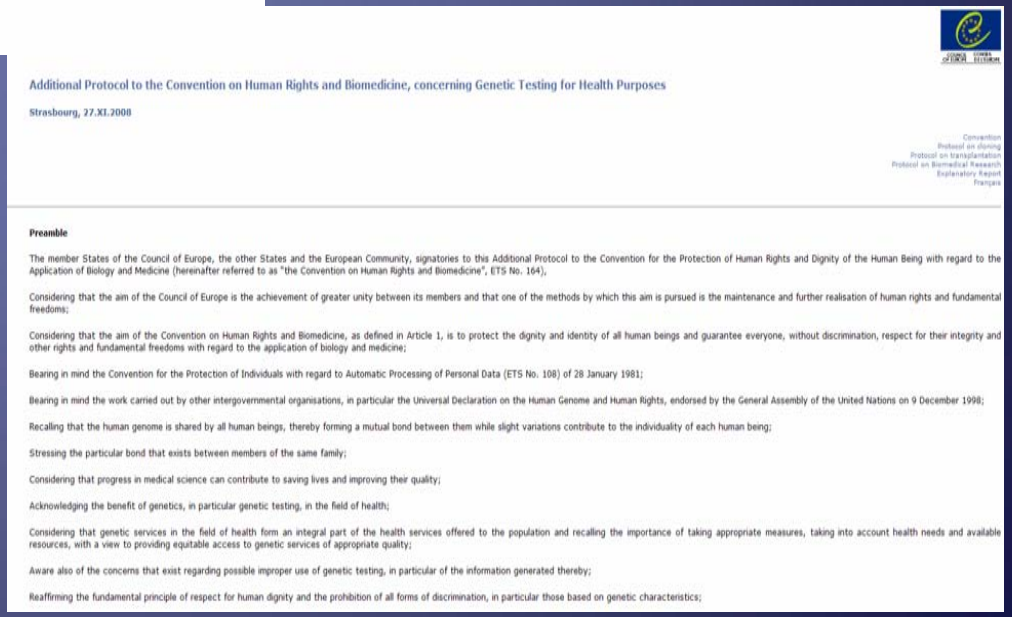
E4. Development of educational and training programmes should be encouraged where they do not exist.

E5. Relevant government or professional authorities should recognise medical genetics as a discipline comprising both a clinical and a laboratory specialty.

E.6 Where governments, regulators and professional bodies recognise medical and scientific qualifications awarded by foreign institutions, such recognition should be extended, as appropriate, to equivalent qualifications in molecular genetic testing.

E.7 All personnel involved in molecular genetic testing should practice within the framework formed by applicable legal, ethical and professional standards.

Addtional protocol to the Convention on Human Rigts and Biomedicine



Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes

Strasbourg, 27.XI.2008

Convention
Protocol on cloning
Protocol on transplantation
Protocol on Biomedical Research
Explanatory Report
Français

Preamble

The member States of the Council of Europe, the other States and the European Community, signatories to this Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (hereinafter referred to as "the Convention on Human Rights and Biomedicine", ETS No. 164),

Considering that the aim of the Council of Europe is the achievement of greater unity between its members and that one of the methods by which this aim is pursued is the maintenance and further realisation of human rights and fundamental freedoms;

Considering that the aim of the Convention on Human Rights and Biomedicine, as defined in Article 1, is to protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine;

Bearing in mind the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (ETS No. 108) of 28 January 1981;

Bearing in mind the work carried out by other intergovernmental organisations, in particular the Universal Declaration on the Human Genome and Human Rights, endorsed by the General Assembly of the United Nations on 9 December 1998;

Recalling that the human genome is shared by all human beings, thereby forming a mutual bond between them while slight variations contribute to the individuality of each human being;

Stressing the particular bond that exists between members of the same family;

Considering that progress in medical science can contribute to saving lives and improving their quality;

Acknowledging the benefit of genetics, in particular genetic testing, in the field of health;

Considering that genetic services in the field of health form an integral part of the health services offered to the population and recalling the importance of taking appropriate measures, taking into account health needs and available resources, with a view to providing equitable access to genetic services of appropriate quality;

Aware also of the concerns that exist regarding possible improper use of genetic testing, in particular of the information generated thereby;

Reaffirming the fundamental principle of respect for human dignity and the prohibition of all forms of discrimination, in particular those based on genetic characteristics;

http://conventions.coe.int/Treaty/EN/Treaties/Html/203.htm

Thank you very much
for your kind help !

milan.macek.jr@LFmotol.cuni.cz