

European Board of Medical Genetics



Clara Serra Juhé
BSc, PhD, President EBMG

Berlin, June 2nd 2024

EUROPEAN BOARD OF MEDICAL GENETICS



**Clinical Laboratory
Geneticists**



**Genetic
counsellors**



**Medical
Geneticists**

The **EBMG** was formed in June 2012 and became a legal entity in June 2014. The EBMG is set up to serve the **needs of patients** who use **genetic services** in Europe through ensuring **good standards of practice** in three professional branches.

EUROPEAN BOARD OF MEDICAL GENETICS



The EBMG Executive Board

The members of the Executive Board are:

- President: Clara Serra-Juhe - Spain
- Past President: Birgitte Diness - Denmark
- Incoming President: Joana Barbosa de Melo- Portugal
- Secretary General: Christophe Cordier - Switzerland
- Deputy Sec General: James O'Byrne - Ireland
- Treasurer: Mohamed El hachmi - Italy

Auditors

- Martina Witsch-Baumgartner - Austria
- Charlotta Ingvaldstad Malmgren - Sweden

Honorary Member

- Ulf Kristoffersson - Sweden
- Heather Skirton - United Kingdom

All members of the Board and Branches offer their services on an entirely voluntary basis and receive no payments for their work. We are grateful for their commitment to this work on behalf of the EBMG.

The Liaison Members (Branch Board Members) nominated by the ESHG are:

- Ellen Heitzer - Austria
- Rebecca Pestoff - Sweden
- Olaf Riess - Germany

CLINICAL LABORATORY GENETICISTS



Members of the (Er)CLG-board

Chair

Thomas Liehr - Germany - present term until 12/2024

Co-Chair

Isabel Carreira - Portugal - present term until 12/2024

Secretary

Martina Rincic - Croatia - present term until 12/2024

Members

Zsofia Balogh - France - present term until 12/2024

Zanda Daneberga - Latvia - present term until 12/2024

Malgorzata Drozniewska - Poland - present term until 12/2024

Karen Heath - Spain - present term until 12/2024

Florentia Fostira - Greece - present term until 12/2024

Amina Kozaric - Bosnia and Herzegovina - present term until 12/2024

Ron Suijkerbuijk - Netherlands - present term until 12/2024

(terms may be prolonged)



CLINICAL LABORATORY GENETICISTS



432 ErCLGs since 15.April 2024 in 42 countries

plus 17 cases pending (group 3), as tests have to be taken

| | | |
|------------------------|-------------|--------------------|
| Armenia | Greece | Russian Federation |
| Austria | Hongkong | Saudi Arabia |
| Belgium | Hungary | Slovakia |
| Bosnia and Herzegovina | India | Slovenia |
| Brazil | Iran | South Africa |
| Bulgaria | Ireland | Spain |
| Canada | Italy | Sweden |
| Croatia | Latvia | Switzerland |
| Cyprus | Netherlands | Thailand |
| Czech Republic | Norway | Turkey |
| Denmark | Pakistan | UAR |
| Finland | Poland | Ukraine / Poland |
| France | Portugal | United Kingdom |
| Germany | Quatar | United States |

- **Online submission system** (July 15th - October 15th)
- **Fees:**
 - 180 € for 5 year registration
 - 100 Euro for 5 year re-registration



CLINICAL LABORATORY GENETICISTS



CLG goal: EU recognition of the profession

“Green Paper” = Professional Qualifications Directive
EU Directive 2013/55/EU was implemented by EU-parliament

**There are 9 EU countries
which CLG recognized as
national profession**

Finland, France, Greece, Hungary, Italy,
Latvia, Poland, Portugal, and Slovenia

States **working** hard on state recognition:
Denmark, Belgium

States **to be members of EU** soon – with
recognition:
North-Macedonia

States **not members of EU** – with **recognition**
Switzerland, UK

In 2023/2024:

contacted national EC members
and to ask them to support us:

Germany - Greece -
Portugal - no reply

Poland – in progress

MEDICAL GENETICISTS



Members

| Name | Country | Term |
|---------------------------|----------------|----------------------|
| Chair | | |
| * Ute MOOG | Germany | 7/2020-12/2024 |
| Members | | |
| * Jonathan BERG | United Kingdom | 7/2021-12/2024 |
| Birgitte Rode DINESS | Denmark | 2022-2026 (2nd term) |
| Thomas MEITINGER | Germany | 2022-2026 (2nd term) |
| James O'BYRNE | Ireland | 2021-2025 |
| Angela PERON | Italy | 2021-2025 |
| * Feliciano RAMOS FUENTES | Spain | 7/2021-12/2024 |
| Cristina RUSU | Romania | 12/2021-12/2025 |
| Delia SABAU | Romania | 2021-2025 |
| * Peter TURNPENNY | United Kingdom | 7/2021-12/2024 |

* Election of 4 Board Members at the meeting of UEM-SMG National Delegates on June 02, 2024, in Berlin

MEDICAL GENETICISTS



European Certificate in Medical Genetics and Genomics (ECMGG)

- Joint development of **UEMS** Section of Medical Genetics, **EBMG-MG** and **ESHG**
- Main **knowledge-based assessment tool**, tests also some aspects of **skills** and **attitudes**
- Helps to establishing **specialty standards** to world class levels **throughout all European countries**
- Assesses knowledge and skills according to the **European Training Requirement** set by UEMS-SMG (new version presented and approved at UEMS Council in Malta on Oct 21, 2023)
- Introduced in **2019** (ESHG conference in Gothenburg), since 2021 **fully online**
- Consists of a **written** and an **oral** part
 - 110 multiple choice questions
 - 6 stations with structured oral assessments



MEDICAL GENETICISTS



Closer cooperation with ESHG

- Representation of ESHG on Branch Board (3 positions)
- Cooperation with ESHG Education Committee, mutual representation
- Representation of UMS-SMG on ESHG website, still to improve
- Support of EACCME application of ESHG conference
- **In preparation:** new Memorandum of Understanding between EBMG, ESHG and UEMS-SMG

European registry of CME events specific to Medical Genetics, e.g. accredited by EACCME or offered by ESHG: checked and abandoned

Plans for the future (to be discussed)

- Course in clinical genetics (in cooperation with ESHG and ITHACA)?
- Programme for genetics/genomics training in mainstream specialties?



GENETIC COUNSELLORS



Genetic Nurse & Genetic Counsellor Branch Board

Chair

- Joana Bengoa - France

Co-Chairs

- Clara Serra - Spain
- Sara Pasalodos - Spain/UK

Members

- Alana Ward - Ireland
- Alekhya Narravula - Germany
- Andrada Ciuca - Romania
- Anna Abuli - Spain
- Irene Esteban Marcos - UK
- Rosie O'Shea - Ireland



GENETIC COUNSELLORS

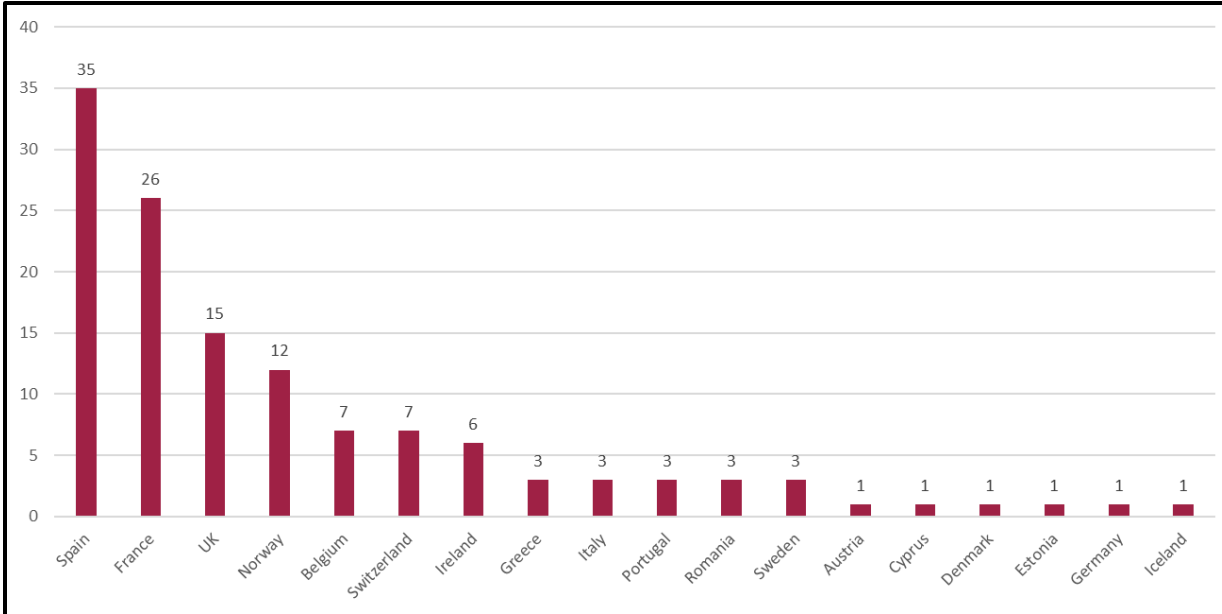


- Assessment of **MSc** in Genetic Counselling curricula
- **Registration** of genetic counsellors via an assessment of a portfolio
- 5-yearly assessment of **renewal** of registration for rGC

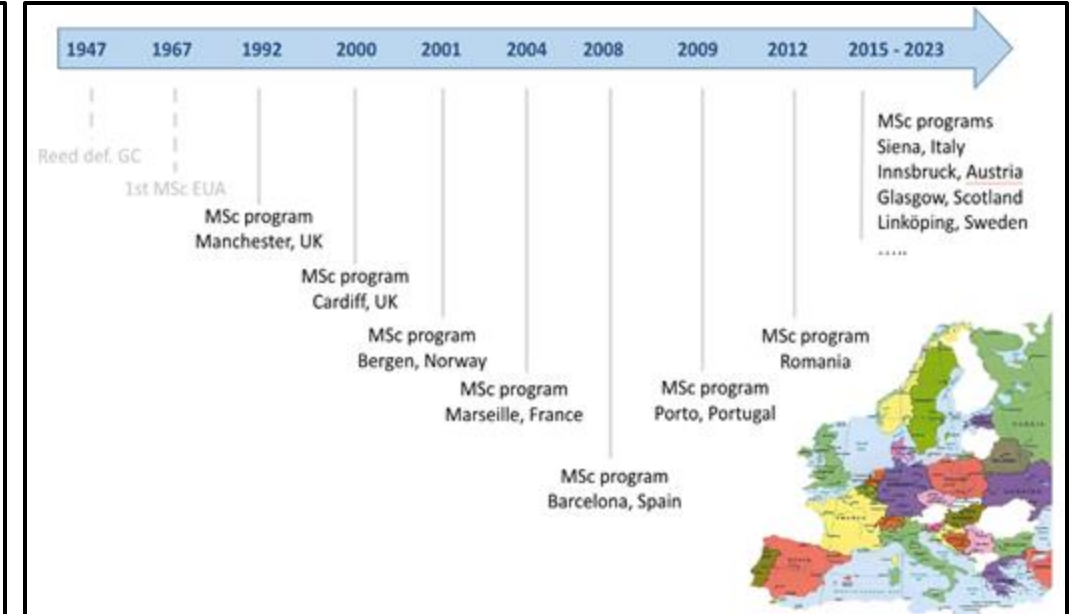
| Type of Application | Evidence Required | | | | | |
|---------------------|----------------------|----------------|---|--------------------|------------------|--------------------------------------|
| | Years of experience* | References (2) | Case log - 50 cases signed by manager or senior colleague | CPD Record (years) | Case studies (2) | Science Essay, Patient Letter & Exam |
| Normal route | 2 years full time | X | X | 2 years | X | |
| National route | 2 years full time | X | | 2 years | | |
| Route A | 4 years full time | X | X | 4 years | X | |
| Route C | 5 years full time | X | X | 5 years | X | X |

* or equivalent part-time

GENETIC COUNSELLORS



129 registered GC
(16 candidates in 23-24 cycle pending)



Currently **9 approved programs**
across **7 countries**



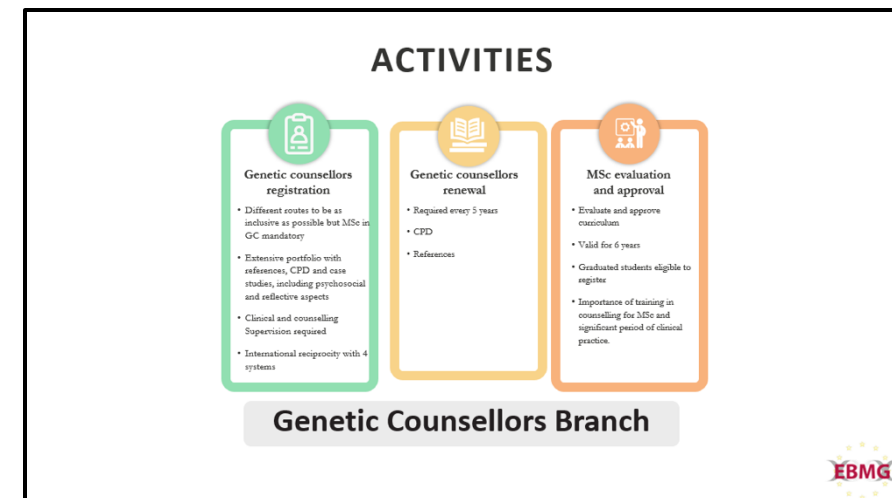
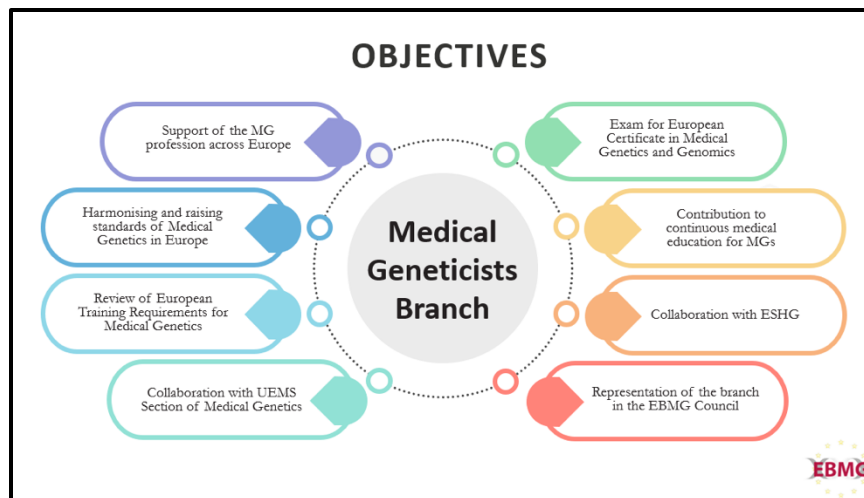
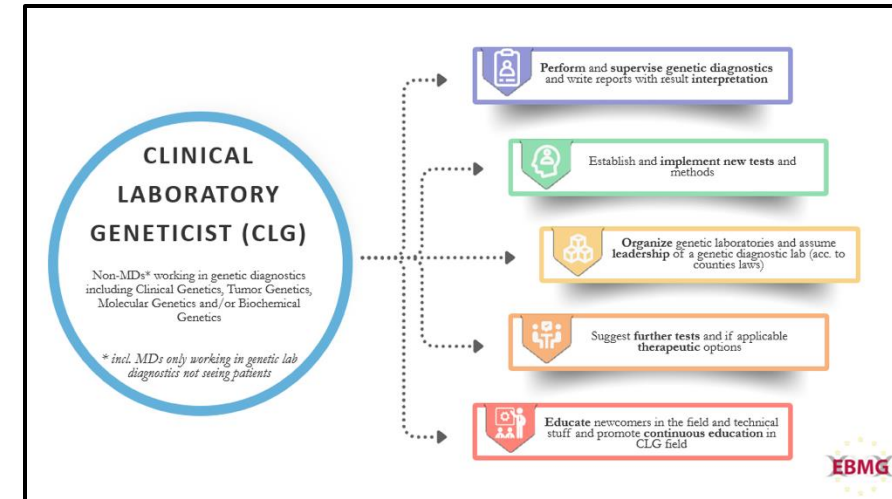
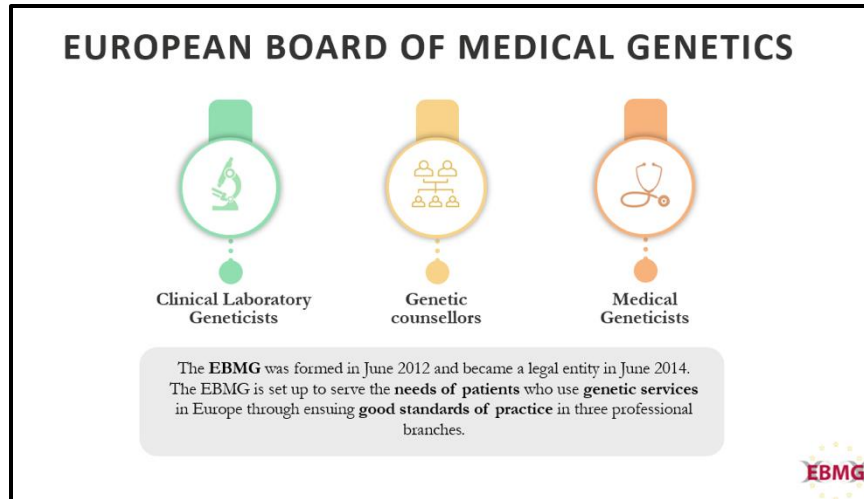
Raising awareness of EBMG

1. Updated **webpage** and the person in charge of the website
2. Visibility at **ESHG**
3. **Linkedin**

EUROPEAN BOARD OF MEDICAL GENETICS




Raising awareness of EBMG



EUROPEAN BOARD OF MEDICAL GENETICS



Building relationships between branches: Job descriptions

 **European Board of Medical Genetics**

Roles of Deputy Secretary of EBMG

General


- Deputy Secretary is a member of both the EBMG Executive and Council
- Participate in the EBMG executive & council meetings
- Support the President and General Secretary of EBMG in their roles

Monthly Council Meetings:

- Support Agenda development and circulation to council members
- Send Invitations to the meetings (Liasé with VMA to ensure correct Meeting Link)
- Record and circulate the minutes of the meetings

General Assembly:

- Support the President & General Secretary in preparing for the GA
- Record and Circulate the Minutes

 **European Board of Medical Genetics**

General Secretary of EBMG: Roles & Responsibilities

General

- General Secretary is a member of both the EBMG Executive and Council
- Participate in the EBMG executive & council meetings
- General Secretary shall be responsible for the organization of the meetings of the GA, the Council and the EXEC, the official agenda, and the minutes of each meeting.

Correspondence to EBMG:

VMA bills per hour. It is fair prices and should not cause concern but if for instance some students are spamming all European organisations with some general questions or if questions come in that the board needs to deal with it may be good to make clear that you do not expect VMA to spend much time processing this.

Council Meetings


At first council meeting:

- Check the invitation and the LINK given by VMA,
- Send the invitation one week before for a reminder.

Council meetings

- Check the agenda with the President and the Deputy Secretary
- Deputy secretary takes minutes – General Secretary supports where needed

General Assembly:

 **European Board of Medical Genetics**

President of EBMG: Roles & Responsibilities

General

- The President is a member of both the EBMG Executive and Council
- Participate in the EBMG executive & council meetings
- The President is responsible for managing the EBMG and represents the EBMG in public, chairs the Council and the EXEC.

Correspondence to EBMG

VMA bills per hour. It is fair prices and should not cause concern but if for instance some students are spamming all European organisations with some general questions or if questions come in that the board needs to deal with it may be good to make clear that you do not expect VMA to spend much time processing this.

At ESHG

NB: Invited to the ESHG board meeting the day before the conference to report.

Newsletter

At the GA in 2022 updates between GA's was requested by board members. One way of doing this is a newsletter, LinkedIn could maybe in the future take over.

The secretaries can be helpful with a newsletter. Should you decide to do it you will also have helped yourself with the annual report that you need to write

**Thank you very much for your
attention**



Berlin, June 2nd 2024