



European Board of Medical Genetics

CURRENT SITUATION OF GENETIC COUNSELLORS AND NURSES

Christophe Cordier, PhD, ErGC 26

Chair of the EBMG – Genetic nurses and Counsellors

14th Meeting of the European Human Genetics Societies

June 2019 – ESHG / NHGS

INTRODUCTION

Genetic Counselling



Sheldon C. Reed, Ph.D.

- suggested the term of “genetic counselling”
- process of communication with patient and family
- genetic counselling would be of help to individual families
- genetic information :
 - “must be compassionate, clear, relaxed, and without a sales pitch.”
 - “given by social workers”

- Genetic Counselling vs Genetic Diagnosis

Genetic Counselling



- International Bioethics Committee, Paris (France), 1995
- Definition of «Genetic Counselling»
 - Process of communication :
 - Explaining a diagnosis,
 - Giving details and informations on the inheritance,
 - Helping patient with Decision of a test.
 - Given by :
 - Medical doctors
 - Nurses (breast nurses)
 - Psychologists
 - Genetic Counsellors (and nurses)



European Board of Medical Genetics

Cardiogenetics

Oncogenetics

Neurogenetics

Genetic Counsellors

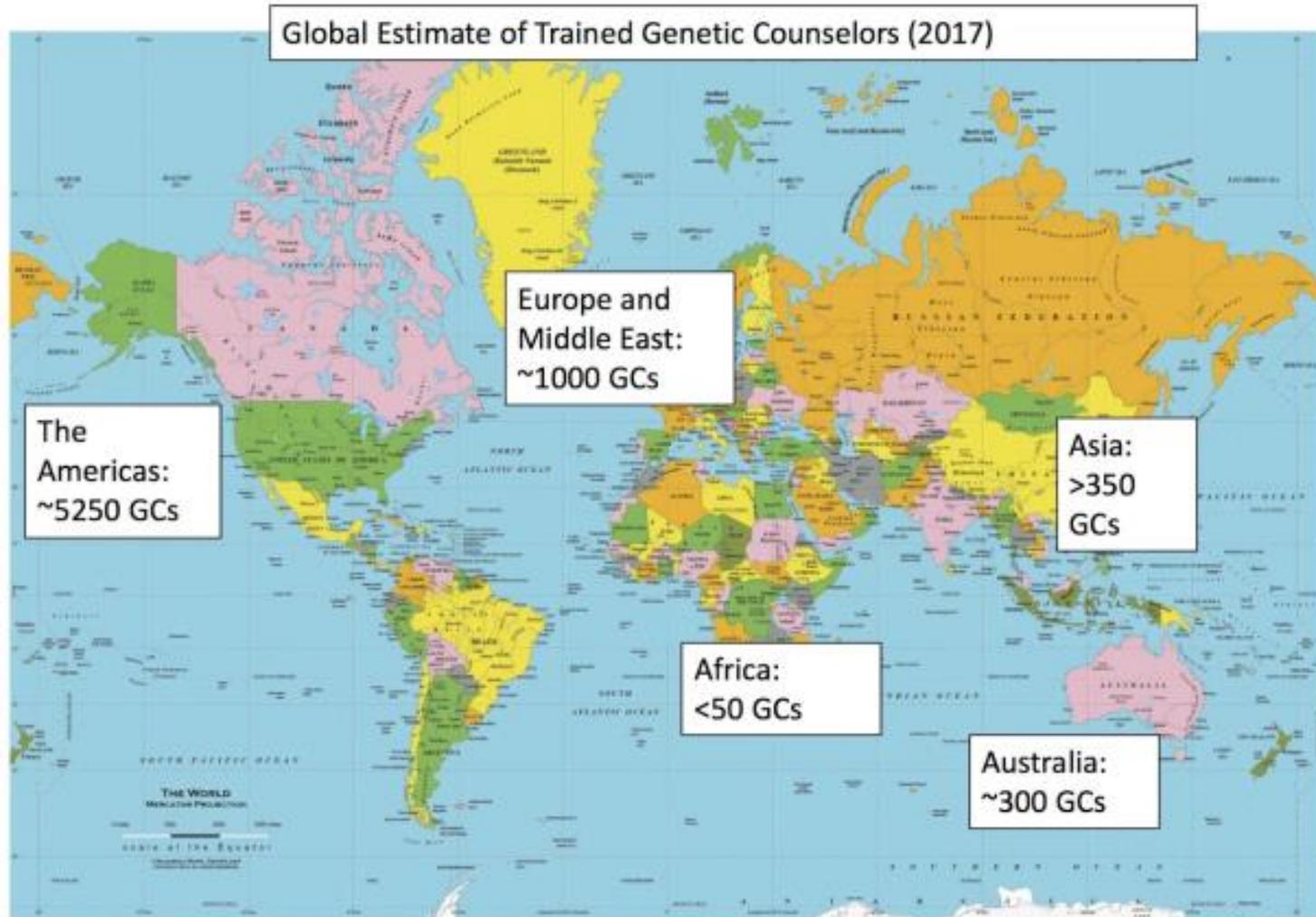
Prenatal Diagnosis

Preimplantation Diagnosis

Medical Genetics

Ophthalmogenetics

Training Programs in Genetic Counselling



Training Programs in Genetic Counselling

Well Established Profession	Developed Profession	Profession In Development (graduate training programs started)	Profession In Development (no MS training programs yet)
United States (1969)	Netherlands (1992)	Saudi Arabia (2005)	China
Canada (1985)	Israel (1997)	South Korea (2006)	Denmark
South Africa (1989)	Norway (2001)	Portugal (2009)	India
Australia/New Zealand (1995)	Japan (2003)	Romania (2009)	Ireland
UK (1992)	Taiwan (2003)	Phillipines (2010)	Malaysia
Cuba (1999)	France (2004)		Singapore
	Spain (2008)	ITALIA ... AUSTRIA ...	Sweden Switzerland



Chair
C.CORDIER



M. Paneque



Chair-Elect
D. Lambert



M. Mc Allister



Co-Chair
C. Serra



I. Bjornevoll



S. Pasalodos



J. Bengoa

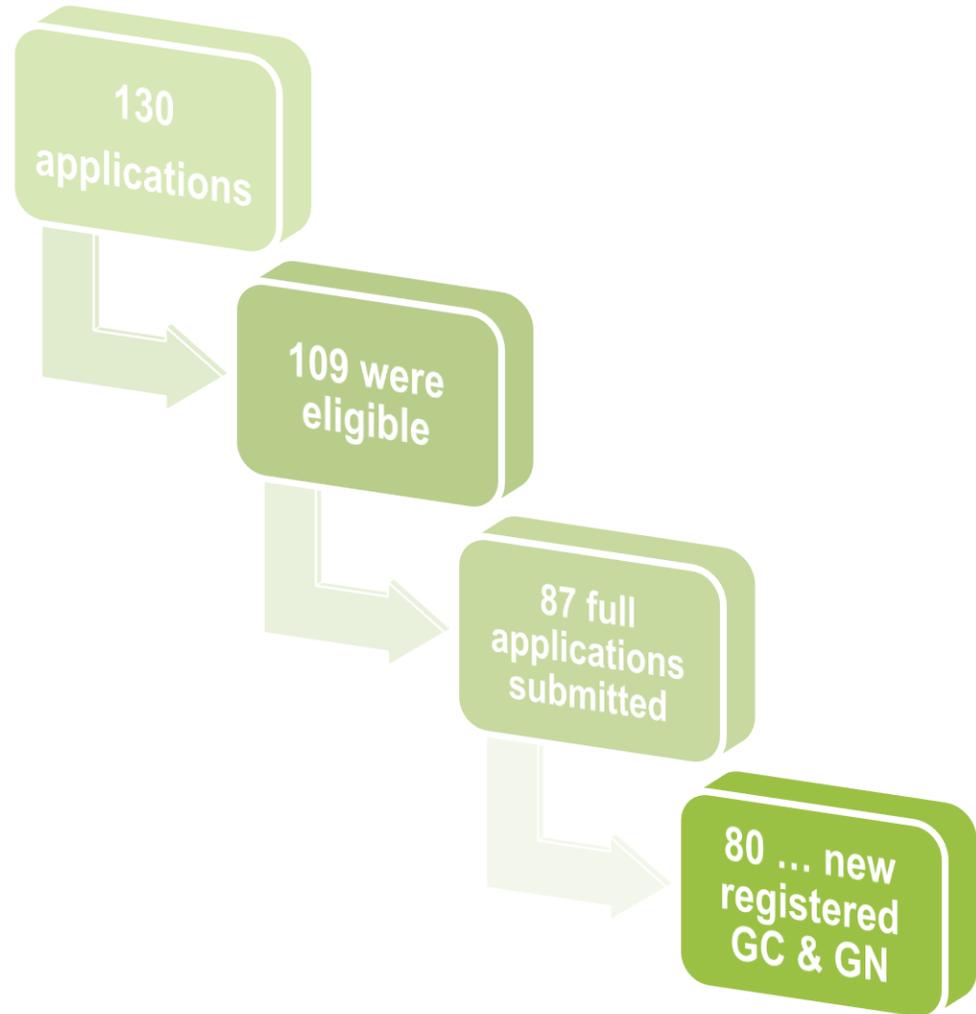


I. Feroce



R. Moldovan





Assessment of the Full Portfolio : 2019

11 Approved

3 deferral request

2 failed

1 major revision (next year)



Training Programs in Genetic Counselling

[Home](#)[News](#)[CLGs](#)[GN & GCs](#)[Med. Geneticists](#)[LGTs](#)[Meetings & Notes](#)[Complaints](#)[Contact](#)

EBMG Home

- [GNGC Home](#)
- [European Registration Process](#)
 - [Key Dates](#)
 - [1. Eligibility to register](#)
 - [2. Practical clinical experience](#)
 - [3. Routes of access to the register](#)
 - [4. Evidences required for the assessment of competences](#)
 - [5. How to apply](#)
 - [6. Fees](#)
 - [7. Maintenance of registration](#)
 - [8. International Arrangements](#)
 - [9. Frequently Asked Questions](#)
 - [Downloads](#)
 - [Online Submission](#)
 - [Timeline](#)
- [European Registration Renewal](#)
- [Registered Genetic Nurses & Counsellors](#)
- [Downloads](#)
- [Fees](#)
- [Related Conferences](#)

Genetic Nurses & Genetics Counsellors

Genetic Nurse & Genetic Counsellor Branch Board

Chair

[Christophe Cordier](#) - Switzerland

Chair-Elect

[Debby Lambert](#) – Ireland

Co-Chair

[Clara Serra](#) – Spain

Members

[Joana Bengoa](#) – France

[Inga Bjornevoll](#) – Norway

[Irene Feroce](#) – Italy

[Marion McAllister](#) - United Kingdom

[Ramona Moldovan](#) - Romania

[Milena Paneque](#) - Portugal

[Sara Pabalodos](#) – United Kingdom



Training Programs in Genetic Counselling

[Home](#)[News](#)[CLGs](#)[GN & GCs](#)[Med. Geneticists](#)[LGTs](#)[Meetings & Notes](#)[Complaints](#)[Contact](#)

EBMG Home

- [GNGC Home](#)
- [European Registration Process](#)
 - [Key Dates](#)
 - [1. Eligibility to register](#)
 - [2. Practical clinical experience](#)
 - [3. Routes of access to the register](#)
 - [4. Evidences required for the assessment of competences](#)
 - [5. How to apply](#)
 - [6. Fees](#)
 - [7. Maintenance of registration](#)

Genetic Nurses & Genetics Counsellors

Genetic Nurse & Genetic Counsellor Branch Board

Chair

[Christophe Cordier](#) - Switzerland

Chair-Elect

[Debby Lambert](#) – Ireland

Co-Chair

[Clara Serra](#) – Spain

- **Assessment of competence of Genetic Nurses and Counsellors in Europe**
- **Proposed European Curriculum for MSc Genetic Counselling**
- **Proposed Code of Practice for Genetic Counsellors in Europe**
- **Proposed Core Competences for Genetic Counsellors in Europe**
- **Proposed Professional and Educational Standards for Genetic Counsellors in Europe**

Relation between medical doctors and non-medical health professionals

European Journal of Human Genetics (2017), 1–6
© 2017 Macmillan Publishers Limited, part of Springer Nature. All rights reserved 1018-4813/17
www.nature.com/ejhg

ARTICLE

Complementariness between medical geneticists and genetic counsellors: its added value in genetic services in Europe

Milena Paneque^{*,1,2,3}, Clara Serra-Juhé^{4,5}, Rebecka Pestoff^{6,7}, Christophe Cordier⁸, João Silva^{1,2,3}, Ramona Moldovan⁹ and Charlotta Ingvaldstad^{10,11,12}

The first emerging theme includes several aspects.

Genetic counsellors, as well as medical geneticists, agreed genetic counsellors frequently acts as **‘patient advocate’**, with a patient-centred approach, focussing on patients’ needs and expectations in the session.

Relation between medical doctors and non-medical health professionals

Genetic counsellors are described as:

- providing additional perspectives and dimensions to the team,**
- Having the ability to get close to patients and families as a whole,**
- Highlighting the psychosocial dimension of the process.**

Genetic counsellor contributions also involved the ethical dimensions of the practice, including research in this area, as well as their knowledge regarding the legal framework.

Genetic counsellors add efficiency to the genetic team. Their influence in genetic services seems to enhance the attention to patients and families at a lower cost, and to provide more accessibility, reduced waiting times, providing autonomous consultations and handling many administrative tasks before and after the appointments.

Relation between medical doctors and non-medical health professionals

The contribution that genetic counsellors provide to genetics health-care services can be summarized as :

- the provision of better care by highly skilled professionals at lower cost,**
- securing greater accessibility and proximity with the patients and families**
- complementing the work with medical geneticists,**
- relevant for the quality of health-care service.**

All the above can be used to argue the need of increased integration of genetic counsellors in countries where they are underutilized and the promotion of professional recognition of genetic counsellors across Europe and worldwide.

European Journal of Human Genetics
<https://doi.org/10.1038/s41431-018-0260-x>



VIEWPOINT



The recognition of the profession of Genetic Counsellors in Europe

Christophe Cordier ¹ · Marion McAllister² · Clara Serra-Juhe³ · Joana Bengoa⁴ · Sara Pasalodos⁵ · Inga Bjornevoll⁶ · Irène Feroce⁷ · Ramona Moldovan⁸ · Milena Paneque⁹ · Debby Lambert¹⁰ · All are member of the Board of the Genetic Nurses and Genetic Counsellors Professional Branch of the European Board of Medical Genetics

Received: 5 July 2018 / Accepted: 14 August 2018
© European Society of Human Genetics 2018



THANKS FOR YOUR ATTENTION