

GECONEU

Genetic counseling in European universities:
the case of neurodegenerative diseases 2021-1-EL01-
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Handbook of the GECONEU course

How to access and navigate the course
How to extend your knowledge

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1. INDEX

1. INTRODUCTION	3
2. INSTRUCTIONS ON HOW TO LOG IN THROUGHOUT THE GECONEU COURSE	4
3. COURSE OVERVIEW	10
4. THE NEXT STEPS. HOW TO EXTEND YOUR KNOWLEDGE	13
4.1. Genetic Counseling Courses in Belgium	13
4.2. Genetic Counseling Courses in Germany	14
4.3. Genetic Counseling Courses in Greece	15
4.4. Genetic Counseling Courses in Spain	17
4.5. Genetic Counseling Courses in <u>Türkiye</u>	21

1. INTRODUCTION

Welcome to the GECONEU Handbook, a comprehensive guide designed to support your journey through the Genetic Counseling e-course, part of the European project "Genetic Counseling in European Universities: The Case of Neurodegenerative Diseases." This handbook serves as an essential companion, providing detailed instructions, course overviews, and resources to enhance your learning experience and extend your knowledge in the field of Genetic Counseling.

Contents of this Handbook:

1. **Instructions on How to Log In Throughout the GECONEU Course:**
 - Step-by-step guidance on accessing and navigating the e-course platform. This section ensures you can efficiently register, select your preferred language, and begin your learning journey without any technical hurdles.
2. **Course Overview:**
 - An in-depth look at the course structure, including detailed descriptions of each unit and lesson. This section outlines the theoretical foundations, practical skills, and ethical considerations covered in the course. You will also find information on quizzes and assessments required to achieve your Certificate of Knowledge.
3. **The Next Steps: How to Extend Your Knowledge:**
 - After completing the GECONEU course, this chapter provides information on further educational opportunities, like programs, specialized training and institutions offering advanced Genetic Counseling education across various European countries.

This handbook is meticulously crafted to ensure you maximize your educational experience in Genetic Counseling. Whether you are a student in the Health and Life Sciences or a professional seeking to enhance your skills, this guide will provide you with the necessary tools and information to succeed in the field of Genetic Counseling for neurodegenerative diseases.

2. INSTRUCTIONS ON HOW TO LOG IN THROUGHOUT THE GECONEU COURSE

By following these steps, you will successfully register for and navigate through the Genetic Counseling e-course offered by the GECONEU project. This course aims to provide essential knowledge and practical skills in Genetic Counseling, specifically focusing on neurodegenerative disorders.

Course Overview: This free e-learning course serves as an introduction to Genetic Counseling in Neurodegenerative Disorders. It encompasses:

- Basic theory on inherited methods and neurodegenerative inherited diseases.
- Ethical aspects of genetics and Genetic Counseling.
- In-depth exploration of main counseling approaches to enhance counseling and communication skills.
- Implementation of Genetic Counseling sessions, including guidelines, protocols, and practical case scenarios.

Target Audience: The course is designed for Health and Life Science and Biomedical Science students, including those in Biology, Medicine, Nursing, Sociology, Psychology, and professionals in Health Sciences interested in Genetic Counseling.

Course Structure:

- **Lessons and Textbooks:** Each lesson includes a presentation of the main lesson and a textbook to extend your theoretical knowledge.
- **Quizzes:** At the end of each lesson, there is a mini-questionnaire. You must complete these quizzes to progress to the next lesson.
- **Case Scenarios:** The course concludes with six practical case scenarios to enhance your practical skills.

Feedback: Before completing the course, participants are required to fill in a feedback questionnaire. This helps improve the course and the learning experience.

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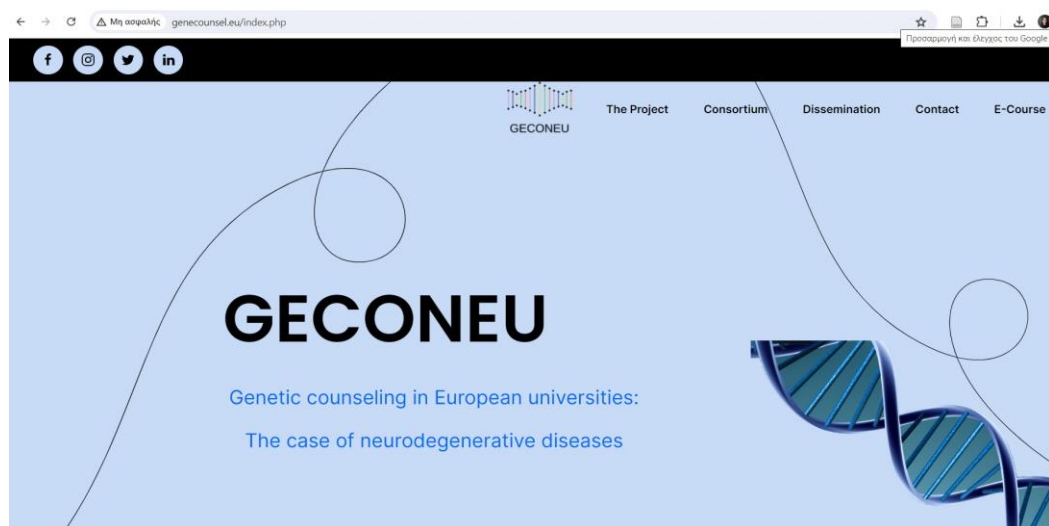
Completion and Certification: Successfully answering the mini-questionnaires for each lesson and achieving a total passing grade of 70% will lead to the issuance of a Certificate of Knowledge.

Further Information: For additional details or any queries, you can find contact information at <http://www.genecounsel.eu/index.php/contact>.

Step-by-Step Guide to Log In and Navigate the GECONEU Course

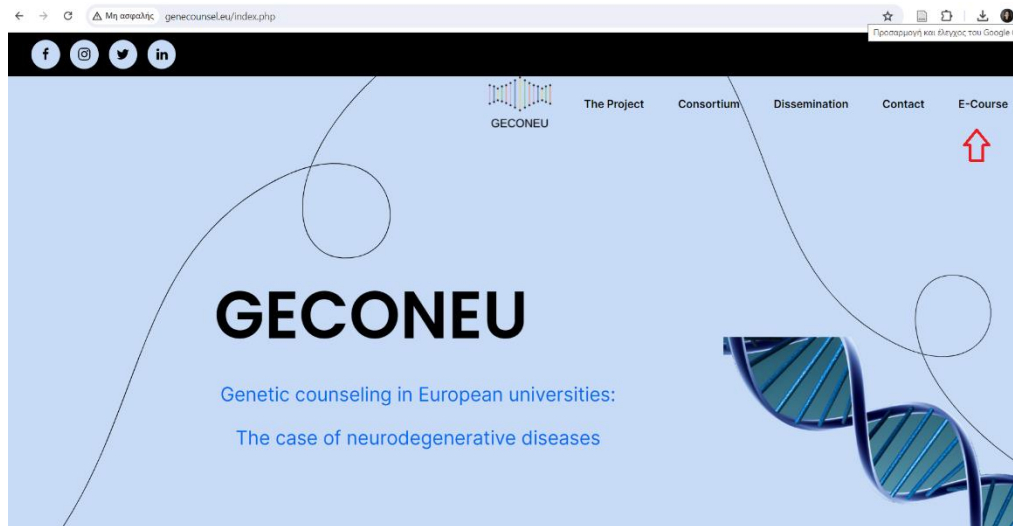
Step 1: Visit the Website

1. Open your web browser.
2. Type in the following URL: <https://www.genecounsel.eu/>.
3. Press Enter to access the homepage, where you will find important information about the project.



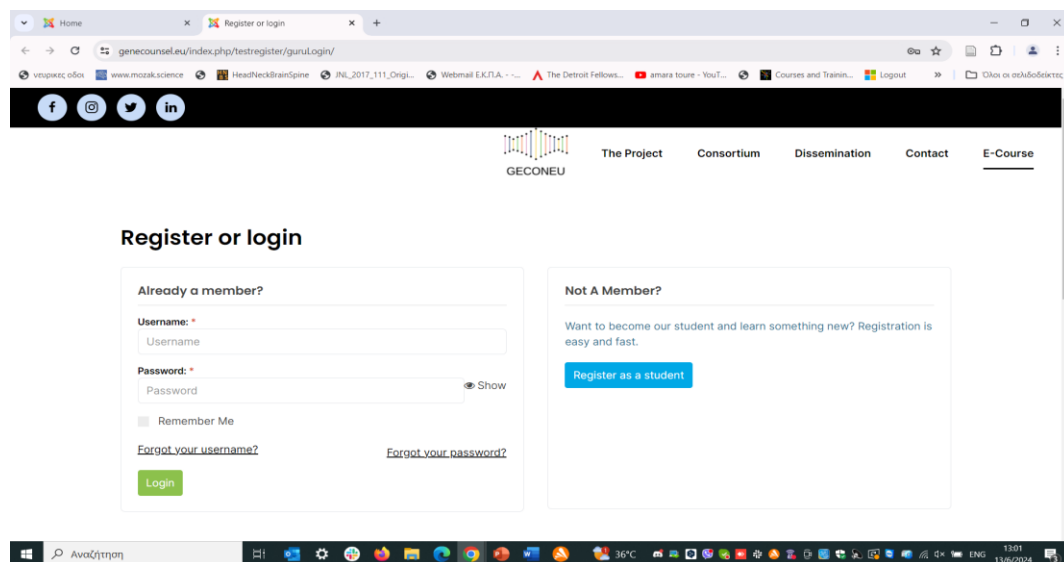
Step 2: Access the E-Course Section

1. On the homepage, locate the "E-Course" section.
2. Click on the "E-Course" link to navigate to the registration page.



Step 3: Register for the Course

1. On the registration page, you will see a form to create an account.
2. Fill in the required details accurately, such as your name, email address, and any other necessary information.
3. Submit the form to complete your registration.

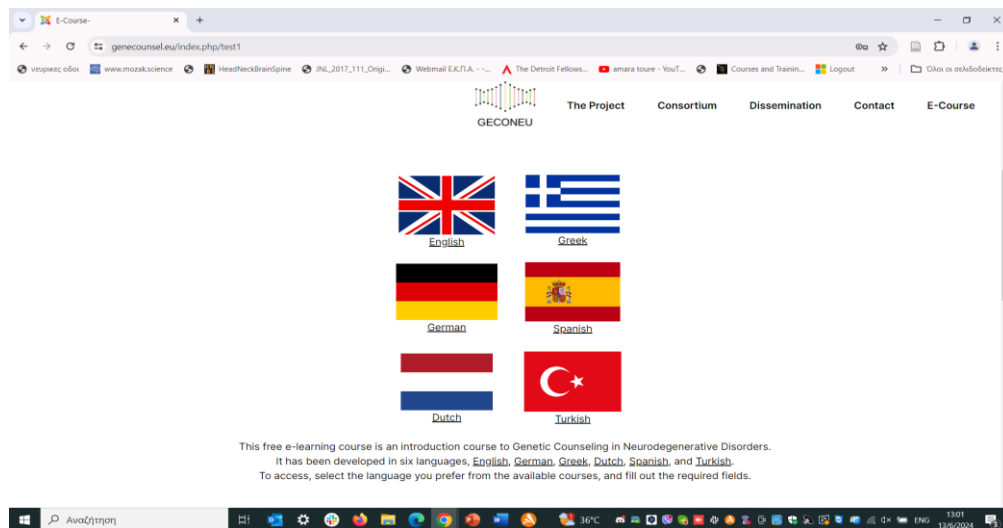


Step 4: Select Your Preferred Language

1. After registering, you will be directed to a page where you can choose your language.

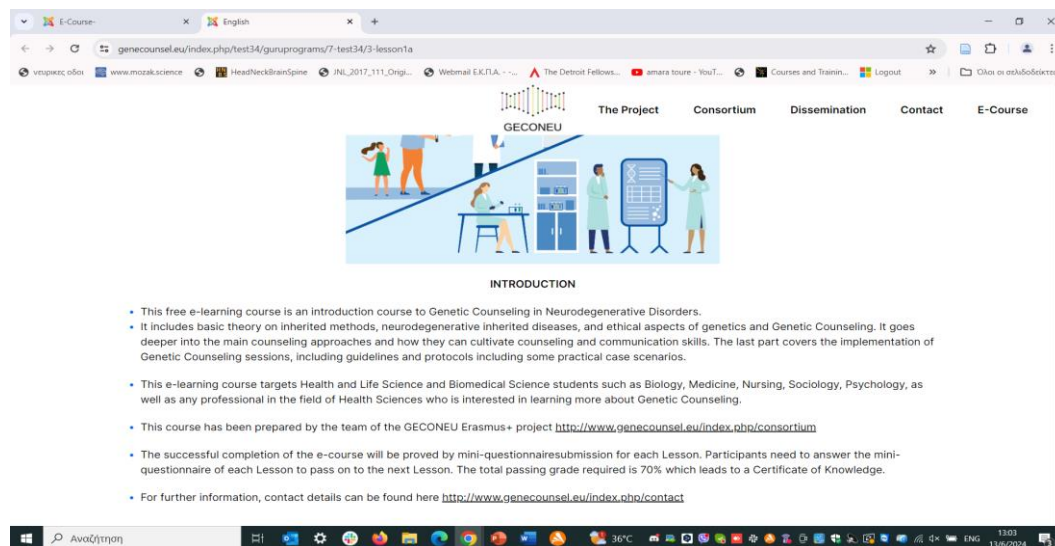
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- The course is available in six languages: English, German, Greek, Dutch, Spanish, and Turkish.
- Click on the relevant flag or language option to enter the course in your chosen language.



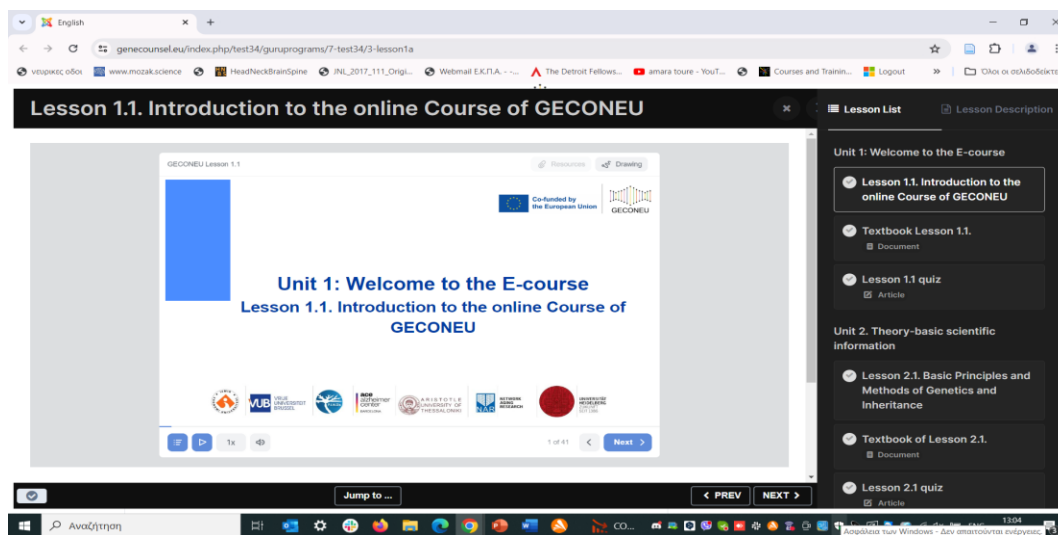
Step 5: Navigate through the E-Course

Now, you have been inserted to the main page of the E-Course. You can find some introductory information and all the units and materials.



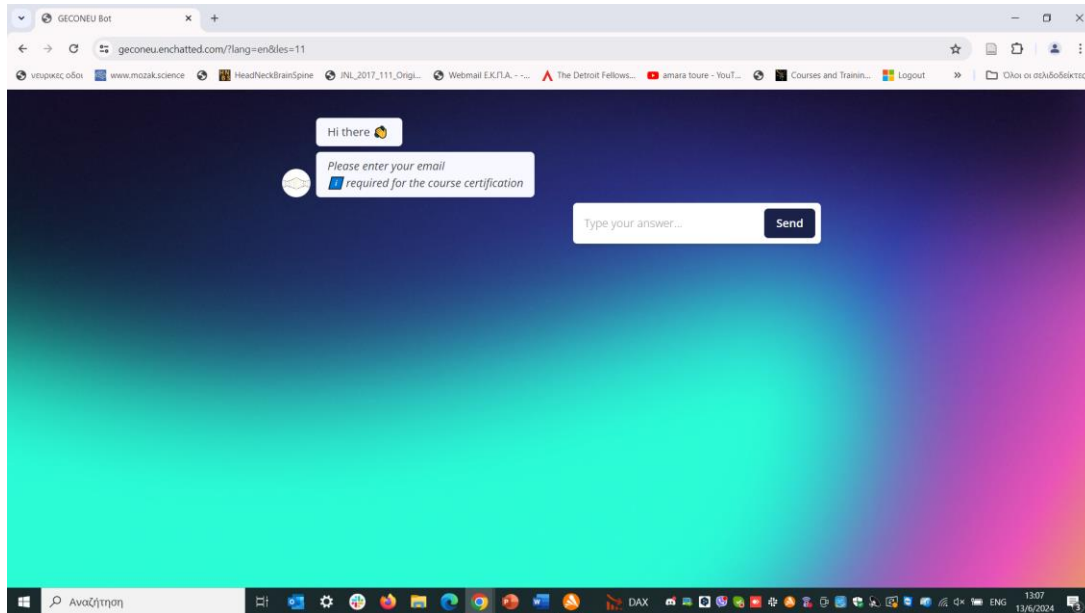
The main structure of the course consists of 5 units which include different lessons and also:

1. **Lessons and Textbooks:** Each lesson includes a textbook to extend your theoretical knowledge.
2. **Quizzes:** At the end of each lesson, there is a mini-questionnaire. You must complete these quizzes to progress to the next lesson.
3. **Case Scenarios:** At the end of the course, there are six practical case scenarios to enhance your skills.
4. **Additional Materials:** A pdf includes more information on how to implement genetic counseling sessions.



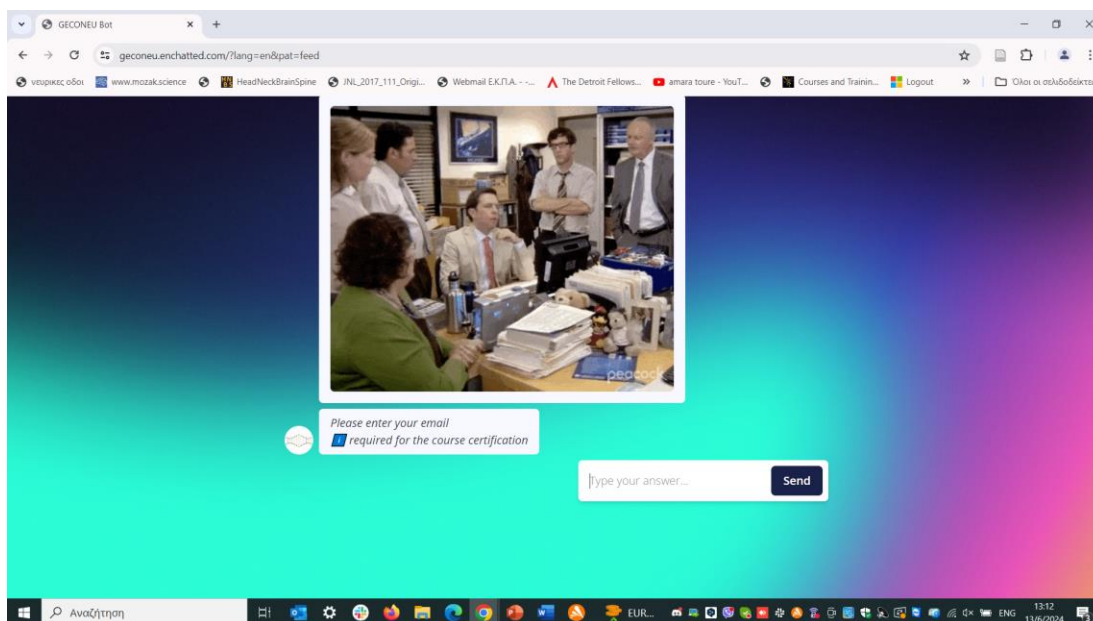
Step 6: Complete the quizzes

1. After studying each lesson, take the mini-questionnaire.
2. Type your email and you can start the quiz
3. A minimum % passing grade of 70% is required to proceed to the next lesson and ultimately earn your Certificate of Knowledge.



Step 7: Fill in the Feedback Questionnaire

1. Before completing the course, fill in the feedback questionnaire provided.
2. This helps improve the course content and overall learning experience.



Step 8: Receive Your Certificate

1. Upon successfully completing all lessons and quizzes, you will receive a Certificate of Knowledge.

Step 9: Seek Further Information if Needed

1. For additional details or any queries, visit the contact page:
<http://www.genecounsel.eu/index.php/contact>.

3. COURSE OVERVIEW

The GECONEU E-Course aims to provide a comprehensive education in Genetic Counseling with a specific focus on neurodegenerative diseases. This structured course is designed to cover fundamental scientific theories, practical counseling approaches, and the implementation of Genetic Counseling sessions. The following is an outline of the units and lessons included in the course.

1. Course Content/ Main Titles

Unit 1: Welcome to the E-Course

- Lesson 1.1: Introduction to Online Courses of GECONEU
 - Overview of the GECONEU project
 - Introduction to the structure and objectives of the E-Course

Unit 2: Theory - Basic Scientific Information

- Lesson 2.1: Basic Inherited Methods and Theories
 - Fundamentals of genetic inheritance
 - Key theories and methodologies in genetics
- Lesson 2.2: Neurodegenerative Inherited Diseases
 - Overview of various neurodegenerative diseases with a genetic basis
 - Understanding the genetic factors contributing to these diseases
- Lesson 2.3: Ethical Aspects of Genetic Counseling
 - Ethical considerations in Genetic Counseling
- Lesson 2.4: Human Rights in Genetics
 - Exploration of human rights issues related to genetic information
 - Legal and social implications of genetic research and counseling

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Unit 3: Counseling and Practice

- Lesson 3.1: The Main Counseling Approaches
 - Examination of different counseling approaches
 - Comparative analysis of counseling methodologies
- Lesson 3.2: Cultivating Counseling and Communication Skills
 - Strategies to develop effective communication skills in Genetic Counseling
 - Practical tips for counseling

Unit 4: How to Implement Genetic Counseling Sessions

- Lesson 4.1: Genetic Counseling Sessions - An Overview
 - Structure and components of a typical Genetic Counseling session
 - Key objectives and goals for each session
- Lesson 4.2: Genetic Counseling Sessions in Practice
 - Practical guidance on conducting Genetic Counseling sessions
- Lesson 4.3: The Use of Telegenetics
 - Introduction to telegenetics and its applications
 - Benefits and challenges of remote Genetic Counseling

Unit 5: GECONEU Project and Evaluation of the Course

- Lesson 5.1: Learn More About the GECONEU Project
 - Detailed information about the GECONEU project, its partners, and objectives
 - Insights into the development and impact of the project

Additional Resources

After each lesson, participants will have access to:

- Additional Resources: Extended reading materials, articles, and multimedia resources to deepen your understanding.
- References: A list of cited works and further reading suggestions.

This structured approach ensures that participants not only gain theoretical knowledge but also develop practical skills essential for effective Genetic Counseling. The E-Course is designed to be comprehensive, interactive, and reflective, preparing students and professionals to excel in the field of Genetic Counseling for neurodegenerative diseases.

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2. How to Read and Work on this Course

To get the most out of the GECONEU E-Course on Genetic Counseling, it is essential to approach it in a structured and methodical way. Below are some guidelines on how to read and work through the course effectively:

1. Start with the Welcome Unit:

- Begin with **Unit 1: Welcome to the E-course**. This unit will introduce you to the GECONEU project and provide an overview of what to expect. Pay close attention to Lesson 1.1, which covers the fundamentals of online learning specific to this course.

2. Follow the Sequential Order:

- The course is designed to build knowledge progressively. Ensure you follow the units and lessons in the given order:
 - Unit 2: Theory - Basic Scientific Information
 - Unit 3: Counseling and Practice
 - Unit 4: How to Implement Genetic Counseling Sessions
 - Unit 5: GECONEU Project and Evaluation of the Course

3. Engage with Each Lesson:

- For each lesson, start by reading the provided textbook material to build your theoretical understanding.
- Participate in any interactive elements such as videos, simulations, or case studies.

4. Utilize Additional Resources:

- At the end of each lesson, you will find **Additional Resources** and **References**. Use these to deepen your understanding of the topics covered.
- Make use of recommended articles, books, and online resources to broaden your knowledge base.

5. Complete Check-Your-Understanding Parts:

- Each lesson includes a **check-your-understanding** section with quizzes or self-assessment tools. These are crucial for assessing your grasp of the material before moving on to the next lesson.

6. Prepare for Assessments:

- At the end of each lesson, complete the mini-questionnaires to test your knowledge.
- Review your answers and understand any mistakes to ensure a solid understanding of the material.

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7. Reflect and Apply:

- The course includes practical elements such as case scenarios in Unit 4. Apply what you have learned in these practical exercises to develop your counseling skills.
- Reflect on your learning after each lesson and consider how the theoretical knowledge can be applied in real-world settings.

8. Complete the Feedback Questionnaire:

- Before finishing the course, fill in the feedback questionnaire. Your insights will help improve the course for future learners.

9. Achieve Certification:

- Successfully completing all the quizzes, you will achieve a Certificate of Knowledge.

By following these steps and actively engaging with the course content, you will be well-equipped with the theoretical and practical knowledge necessary for a successful career in Genetic Counseling, particularly in the context of neurodegenerative diseases.

4. NEXT STEPS. HOW TO EXTEND YOUR KNOWLEDGE

To find further courses and training opportunities in the Genetic Counseling field, you can search on the website of the European Board of Medical Genetics (EBMG) <https://www.ebmg.eu/669.0.html> as well as other numerous validated Master's degree programs in Europe <https://www.ebmg.eu/959.0.html>. The EBMG is the establishment of professional standards of education, training, and practice in human and medical genetics and genetic counseling, by developing and administering systems of certification and/or re-certification for professionals working as specialists in genetic healthcare in Europe.

4.1. Genetic Counseling Courses in Belgium

Belgium has eight different medical genetic centers, connected to eight different universities and university hospitals. All these universities provide a Medical Genetics specialization program for MD's. This Master-after-Master, with the aim to form fully qualified Clinical Geneticists, has some different nuances across the different universities. But overall, it takes a total of 6 years of training with a lot of practice in the form of

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internships at the clinical routine practice for one to become a Clinical Geneticist. Genetic counseling experience is obtained throughout the residency period. Courses' content include enhancing the knowledge and attitudes of the doctors in the field of medical genetics, understanding novel findings in research and being communicative in different contexts.

Genetic counselors are not officially recognized by the state (yet). **If one wants to become a genetic counselor in Belgium, they have to complete exams at the European level** (European Board of Medical Genetics: <https://www.ebmg.eu/408.0.html>). There is one certified course on GC, organized by one of the universities of Flanders (Universiteit Gent) that prepares graduates to work in medical genetic centers. This postgraduate is aimed for students who already acquired a bachelor degree in Nursery or a master in Biomedical Sciences / Psychology. The topics of the course include "Principles of genetics", "Genome diagnostics", "Genetic diseases" and "Genetic counseling". The total duration of the course is two years, with an estimate of 177 hours of practice in GC over the entire second year of the training. More information can be found on the website: <https://studiekiezer.ugent.be/2024/postgraduate-certificate-genetic-counseling>

The Belgian Society of Human Genetics (BeSHG) also organizes an annual interuniversity course on Medical Genetics. The content is broad, with one specific lecture focused on GC and risk assessment. This theoretical course takes place once per month for a total of eight months. More information on the website: <https://beshg.be/>

4.2. Genetic Counseling Courses in Germany

In Germany, the practice of genetic counseling and genetic testing is regulated by the *Gendiagnostikgesetz* (Genetic Diagnostics Law). According to this legislation, only physicians with a medical degree are authorized to conduct genetic counseling.

There are three specific pathways to qualify for providing genetic counseling in Germany:

1. Human Geneticists: Medical graduates who have completed specialized training in human genetics.
2. Specialized Physicians: Physicians who have completed a 72-hour course in genetic counseling within their area of expertise (subject specific course in genetic counseling, e.g., oncologists taking a course on cancer genetics).

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3. Supervised Physicians: Physicians who are supervised by a human geneticist specialist.

Therefore “Genetic Counseling Courses” in Germany are to this date only available for physicians/medical graduates. Genetic counseling necessitates either

1. specialist training following medical school, which involves a 60-month residency
2. subject-specific course in genetic counseling: a 72-hour course for medical specialists in their respective fields. For example, oncologists (cancer experts) may complete a 72-hour course specifically focused on genetic counseling related to cancer genetics. Similarly, psychiatrists or neurologists may take a 72-hour course on genetic counseling pertaining to psychiatric or neurodegenerative disorders. More information on the 72-hour courses can be found [here](#).

For German-speaking Readers Interested in Genetic Counseling Without Graduating in Medicine: There is a German-speaking Master’s programme in Genetic Counseling at the University of Innsbruck, Austria. More information about the programme can be found [here](#) and in the [informational leaflet](#).

However, in Germany, those trained outside the country can only practice genetic counseling domestically under the supervision of human geneticists who were trained in Germany.

Two years ago, the *Gesellschaft für Humangenetik* (Society for Human Genetics) applied to the *Bundesministerium für Gesundheit* (Federal Ministry of Health) to recognize genetic counseling assistants as a non-medical profession. However, the Ministry has yet to respond to this application.

4.3. Genetic Counseling Courses in Greece

In Greece, there is no national regulation in order to work as a genetic counselor. Genetic counselors do not need a certification to practice. In Greece, currently, genetic services are provided by physicians in collaboration with clinical laboratory geneticists due to the absence of medical geneticists and genetic counselors.

While opportunities for genetic counseling training in Greece are still limited, there are several advanced education programs available through various universities and

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institutions. Below is an overview of master programs, specialized training courses, universities offering these programs, course details, and admission requirements.

Master of Science (MSc) in Human Genetics and Genetic Counseling

- **Institution:** University of Thessaly
- **Course Details:** This program aims to provide a high level of education and specialization in the constantly evolving field of Human Genetics, as well as the acquisition of expertise in the diagnosis of genetic diseases.
- **Duration: 1 year (Full-time)**
- **Admission Requirements:**
 - Bachelor's degree in Biology, Medicine, Nursing, Psychology, or a related field.
 - Proficiency in English.
 - Entrance examination and/or interview.
- **Website:** <https://www.med.uth.gr/pmsgenetiki/index.html>

E-learning in Genetic Counseling

- **Institution:** National and Kapodistrian University of Athens, e-learning
- **Course Details:** This program combines theoretical knowledge with practical training in genetic counseling. It covers medical genetics, counseling techniques, ethical issues, and research methods.
- **Duration: 3 months (72 hours)**
- **Website:** <https://elearningekpa.gr/courses/genetiki-sumbouleitiki>

Master program in Neurosciences and Neurodegenerative Disease

- **Institution:** Aristotle University of Thessaloniki, online and onsite.
- **Course Details:** The Program aims at the professional empowerment of Biomedical Sciences graduates, not only by providing theoretical knowledge on the epidemiology, diagnosis, pathogenesis and treatment of Neurodegenerative Diseases, but also by involving them in processes of mental, moral and emotional development, reflection and personal -professional emancipation in practice close to patients and caregivers, in order to become more effective in dealing with patients with these problems. Thus, the Program is expected to ensure for the

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trainees qualifications that meet the needs of the labor market and facilitate their professional absorption by similar bodies.

- **Duration: 1 year (Full-time)**
- **Website:** <http://www.neuromed-auth.gr/>

Master of Science (MSc) in Medical Genetics: Clinical and Laboratory direction

- **Institution:** National and Kapodistrian University of Athens, Medical School
- **Course Details:** During the semesters, students are required to attend lectures covering a total of 11 compulsory courses, as well as workshops on laboratory practices, case studies in medical genetics and genetic counseling.
- **Duration: 1,5 year (3 semesters)**
- **Website:**
https://school.med.uoa.gr/metaptychiakes_spydes/programmata_metaptychiakon_spydon_eisachthentes_apo_to_akad_etos_2018_19/pms_iatrikis_scholis/iatriki_genetiki_kliniki_kai_ergastiriaki_kateythynsi/

4.4. Genetic Counseling Courses in Spain

In Spain, the right to receive genetic counseling every time we undergo a genetic test is established in the 14/2007 law of biomedical research that:

Article 55. Genetic Counseling.

- 1. When a genetic analysis is carried out for health purposes, it will be necessary to ensure appropriate genetic counseling for the individual concerned, in the manner determined by regulations, always respecting the individual's criteria.*
- 2. The professional conducting or coordinating genetic counseling must provide appropriate information and guidance regarding both the significance of the resulting genetic diagnosis and the possible alternatives available to the individual based on that diagnosis.*

However, as mentioned in the second paragraph, it is not established what kind of professional should provide this kind of service or what kind of qualifications they should possess.

Moreover, there's a shortage of professionals equipped to provide comprehensive genetic counseling, especially for neurodegenerative diseases, due to the lack of legislation and training programs.

The Spanish Society of Genetic Counseling (SEAGen) adheres to European guidelines due to the absence of national legislation. Therefore, Spain can offer one of the few master recognized by the European Board of Medical Genetics (EBMG) to become a certified genetic counselor:

UAB Official Master's Degree in Healthcare Genetics

- **Institution:** Autonomous University of Barcelona (UAB)
- **Course Details:** This program focuses on evaluating a patient's clinical and family history and the results of previous genetic studies to determine inheritance models and identify family members at risk. It covers risk assessment, advanced communication skills for conveying complex concepts and understanding the psychosocial aspects of genetic disease diagnosis. The program also emphasizes non-directive genetic counseling and the ability to review and improve one's practice.
- **Duration:** 1 year and 10 months
- **Admission Requirements:** Graduates in Life and Health Sciences (Biology, Biomedicine, Genetics, Biochemistry, Nursing, Pharmacy, Medicine, Psychology, and related fields), Graduates in Medicine and Surgery for Clinical Genetics specialization.
- **Website:** [UAB Official Master's Degree in Healthcare Genetics](#)

Additionally, Spain offers the following training courses:

- **UAB Official Master's Degree in Advanced Genetics**
- **Institution:** Autonomous University of Barcelona (UAB)
- **Course Details:** This program introduces genomic medicine applications in diagnosing, understanding, and treating genetic diseases. It includes bioinformatics analysis of genetic variants, databases, and variant filtering, with a foundation in genetic counseling.
- **Duration:** 8 months
- **Admission Requirements:** Bachelor's or bachelor's degree in any Biosciences, Medicine, Pharmacy, Veterinary Medicine, or related fields and proficiency in English (100%).

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- **Website:** [UAB Official Master's Degree in Advanced Genetics](#)

Course: Expert in Genomic Medicine and Genetic Advice

- **Institution:** EADE (Málaga)
- **Course Details:** This program highlights genomics as central in medical practice, emphasizing the necessity for health professionals to be trained in Genetic Counseling. The course focuses on integrating genetic studies into Genetic Counseling consultations, with a specific focus on Epilepsy, Intellectual Disability, and Autism.
- **Duration:** 300 hours
- **Admission Requirements:** Not mentioned
- **Website:** [Expert in Genomic Medicine and Genetic Advice](#)

Course: Genetic Counseling in Clinical Practice

- **Institution:** Genotipia
- **Course Details:** This course provides a validated program by the National Spanish Health System, focusing on the interpretation and transmission of complex genetic information. It covers genealogical trees, inheritance patterns, counseling skills, and clinical case studies, emphasizing the bidirectional nature of genetic counseling.
- **Duration:** 15 hours
- **Target:** Clinical and health professionals using genetic tests in their daily practice, Future genetic counselors and clinical geneticists, students in biomedical and health sciences areas, anyone interested in the work of genetic counselors.
- **Website:** [Genetic Counseling in Clinical Practice](#)

Diploma in Genetic Counseling and Clinical Genomics

- **Institution:** University of Valencia
- **Course Details:** This diploma aims to provide knowledge and competencies in Genomics for clinical settings, focusing on conveying genetic information to patients and supporting decision-making. It addresses the technical and scientific advances in Genomics, the public health challenges of genetic diseases, and the need for professionals skilled in current genomic technologies.
- **Duration:** 1 year, 30 ECTS
- **Admission Requirements:** Graduates in Health Sciences (Medicine, Pharmacy, Biotechnology, Biology, Chemistry, Biochemistry, etc.), Nursing, and Psychology,

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other health professionals with approval from the Academic Direction, residents and practitioners seeking to expand or update their knowledge in Genetics.

- **Website:** [Diploma in Genetic Counseling and Clinical Genomics](#)

Master's Degree in Clinical Genetics and Rare Diseases

- **Institution:** University of Barcelona in collaboration with Sant Joan de Déu Hospital
- **Course Details:** This program provides education in clinical genetics with a focus on rare diseases. It is designed for professionals specializing in pediatrics, other medical and health specialties, or those with a master's degree in human genetics aiming to specialize in clinical genetics and rare diseases. The program includes genetic counseling for prenatal screening.
- **Duration:** 2 years (120 ECTs)
- **Admission Requirements:** Graduates in Medicine, specializing in pediatrics, internal medicine, obstetrics and gynecology, or other medical specialties, graduates in Biology, Pharmacy, or Biochemistry with BIR, FIR, QIR specialization, Graduates with a Master's in any area of Human Genetics/Genomics.
- **Website:** [Master's Degree in Clinical Genetics and Rare Diseases](#)

Professional Master's Degree in Clinical Genetics

- **Institution:** Tech School of medicine
- **Course Details:** Developed by professionals from various Clinical Genetics clinics, this program combines theoretical knowledge and practical case studies. It covers the management of hereditary disorders in genetic counseling, prevention programs, and prenatal and preconception counseling. The program includes theoretical texts and practical clinical examples.
- **Duration:** 1 year (1,500 hours)
- **Admission Requirements:** Not specified
- **Website:** [Professional Master's Degree in Clinical Genetics](#)

4.5. Genetic Counseling Courses in Türkiye

In Türkiye, genetic counseling is regulated by the Regulation on Genetic Diseases Diagnostic Centers. Although Article 14 of Regulation on Genetic Diseases Diagnostic Centers grants this authority to a medical doctor who is an expert in the field of genetics or has the title of doctor of science, **the regulation also gives authority to medical biology or genetics specialists or biochemistry and clinical biochemistry specialists.** According to the

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current rules, genetic counseling in tertiary genetic centers has to be provided by medical doctors only, and among them, specialists in medical genetics, perinatology, or obstetrics and gynecology are mostly the specialties in giving genetic counseling.

In Türkiye, the medical genetics specialty program is a 4-year program after obtaining the medical doctor degree. Healthcare professionals such as physicians, nurses, midwives, and biologists are increasingly interested in becoming a team member of genetic counseling headed by a physician who is experienced in genetic counseling. However, no specialized training programs or certification courses are available for these professionals.

There is no regulation or law that specifically determines the characteristics of a genetic counselor. Genetic counseling is mandatory for all genetic tests. However, the nature of counseling and pre-and post-test counseling sessions are not clearly defined in the regulation. Türkiye ratified the Oviedo Protocol in 2020.