

HEALTH POLICIES ABOUT RARE DISEASES.
THE CASE OF MYASTHENIA GRAVIS (MG).
MYASTHENIC PATIENTS DEMOGRAPHIC
DATA ANALYSIS AND STUDY OF THEIR LIFE
QUALITY

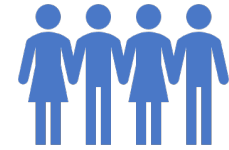
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What is Myastheni a Gravis (MG)?

It is an autoimmune neuromuscular disease caused by a defect in the action of a chemical called acetylcholine at neuromuscular junctions, which transfers the stimuli from the nerves to the muscles through said chemical and causes weakness in the skeletal muscles of multiple severity levels.

Epidemiology of MG

- Rare autoimmune disease
- Its prevalence has been calculated in various studies at 5-15 patients per 100.000 individuals.
- It is rarer than Multiple Sclerosis (60-100 patients /100.000 individuals), or Parkinson's Disease (100/100.000 individuals).
- The last 50 years, MG's appearance is stably increased in Western European countries.
 - In the UK, in 1934 it was 2,6/100.000 while in 1998 it was 15
 - In Denmark, in 1970 it was 2/100.000 while in 1988 it was 7,7
 - In Greece, the prevalence is 8,2/100.000



Features of MG

- Pathogeny
- Clinical Image
- Diagnosis
- Treatment

Clinical Classification of the Myasthenia Gravis Foundation of America (MGFA)

1. Ocular muscle weakness; all other muscle strength is normal.
2. Mild weakness affecting muscles other than ocular muscles; there may also be ocular muscle weakness of any severity.
3. Moderate weakness affecting muscles other than ocular muscles; there may also be ocular muscle weakness of any severity.
4. Severe weakness affecting muscles other than ocular muscles; there may also be ocular muscle weakness of any severity.
5. Respiratory insufficiency with intubation and mechanical ventilation of the patient.

We need to shape health policies for rare diseases and MG

- They are serious disease cases, chronic, often degenerative as well as life-threatening.
- They often cause incapacities that decrease the patient's autonomy leading to a lower quality of life.
- 50% of MG patients have the first symptoms at childhood.
- They are incurable diseases, most of them having a bad prognosis at their treatment approach.
- They cause psychological damage.
- The families face great difficulty in finding the proper treatment.



Points of interest

- Action for rare diseases in Europe
- Strategic applications for rare diseases and MG in Greece
- Main blocks of activities to apply the national action plan

Table: Total cost budget of rare diseases per stage

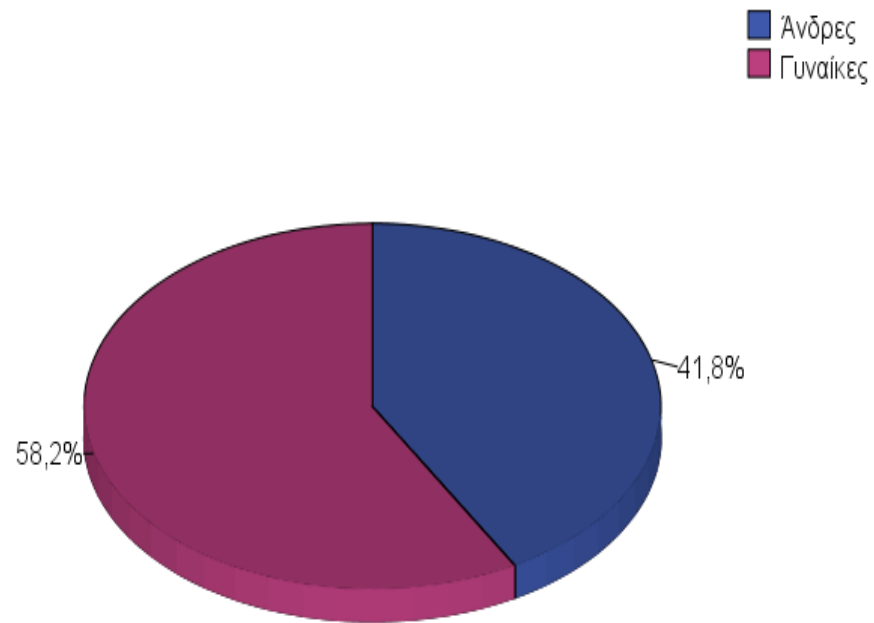
A/A	Stages	Total Cost (€)
1	Early diagnosis	1.500.000
2	Treatment	500.000
3	Social healthcare – recovery	15.863.332
4	Research	1.454.217
5	Education	7.952.858
6	Corporate-responsibility-based development strategy	433.427

FINANCIAL BURDEN-
RISK CAUSING-
GENERICS

Case Study

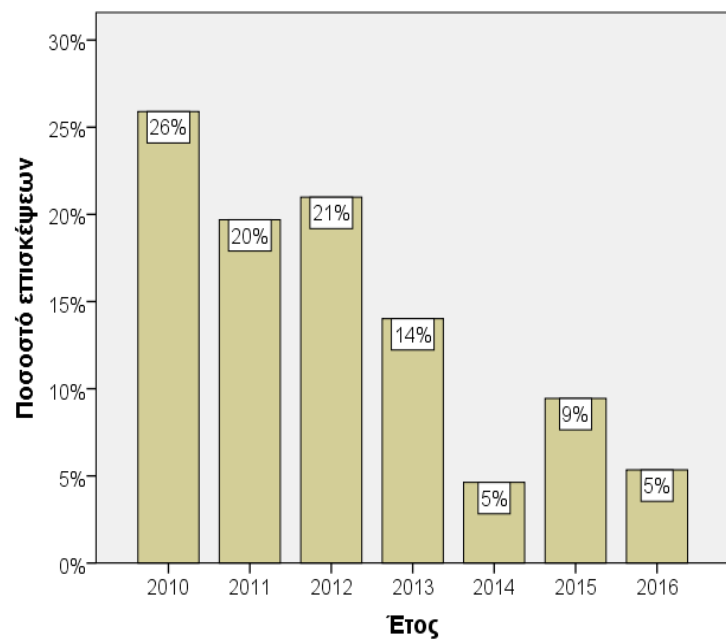
- Sample: patients who did diagnostic blood tests for the control of MG antibodies between 2010 and 2016.
- Aim: register the appearance of new incidents and the prevalence in the registered population (Neuroimmunology Paster Laboratory, Tzartos Neurodiagnostics)
- We study the appearance of new incidents per age group, gender, month of appearance, year of appearance and region.

MG appearance in men and women



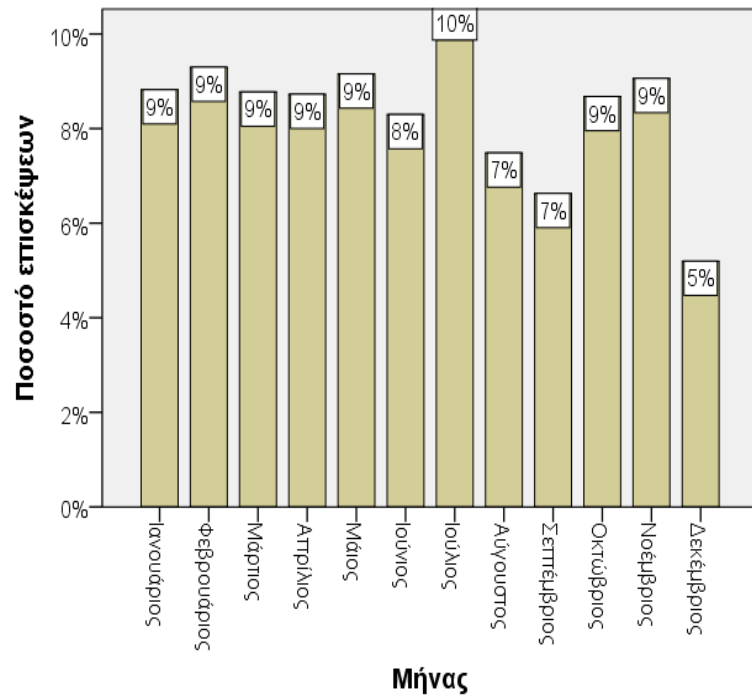
	Frequency Number (N)	Percentage (%)
Men	876	41,8
Women	1221	58,2
Total	2097	100%

MG appearance per year



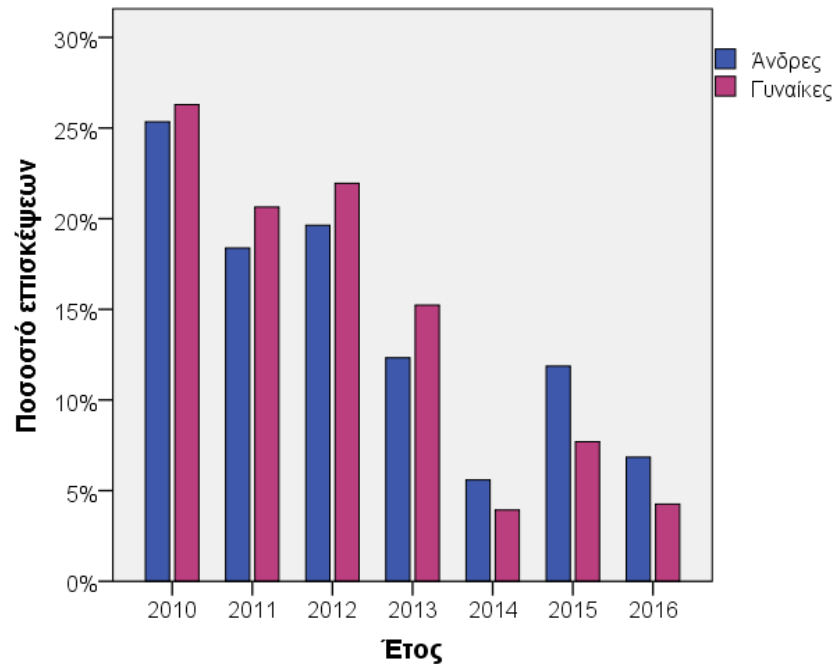
Year	Frequency	Percentage (%)
2010	543	25,9
2011	413	19,7
2012	440	21,0
2013	294	14,0
2014	97	4,6
2015	198	9,4
2016	112	5,3

MG appearance per month



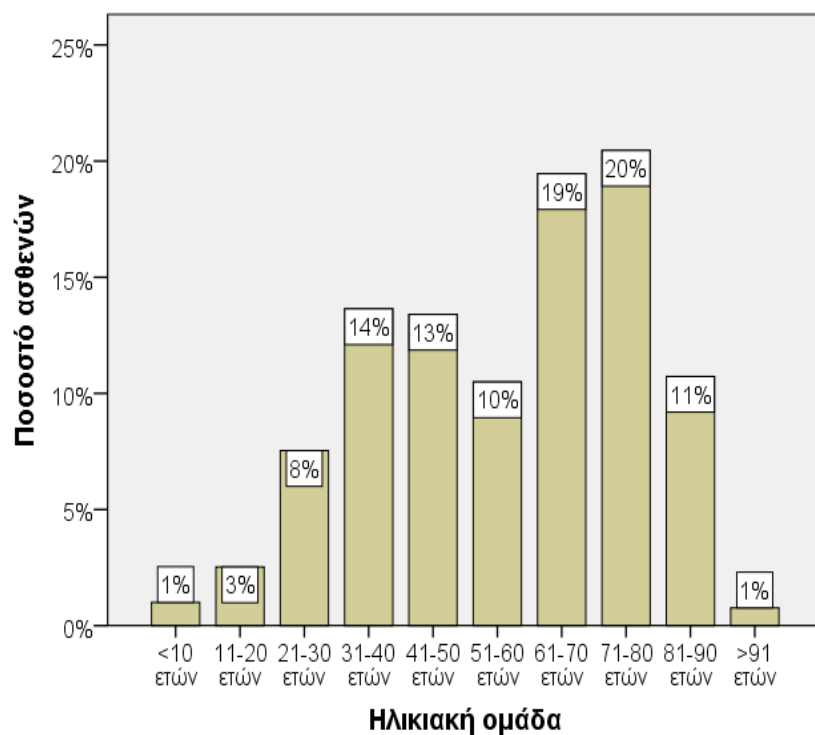
Month	Frequenc y	Percentage (%)
January	185	8,8
February	195	9,3
March	184	8,8
April	183	8,7
May	192	9,2
June	174	8,3
July	207	9,9
August	157	7,5
September	139	6,6
October	182	8,7
November	190	9,1
December	109	5,2

MG appearance in men and women per year



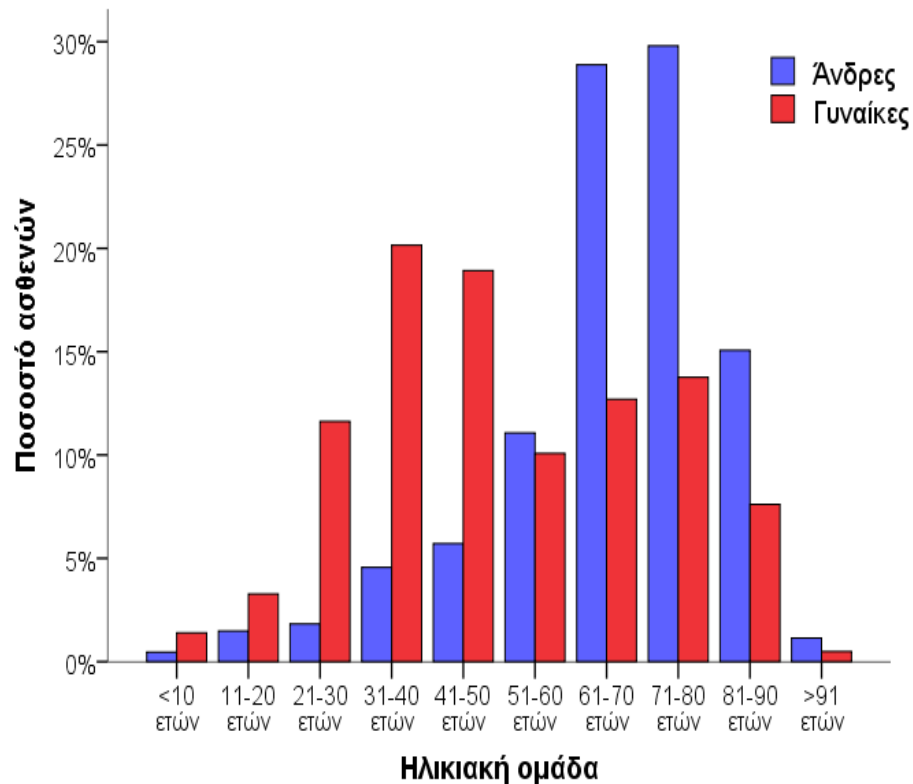
Year	MEN		WOMEN	
	Frequency	Percentage (%)	Frequency	Percentage (%)
2010	222	40,9%	321	59,1%
2011	161	39,0%	252	61,0%
2012	172	39,1%	268	60,9%
2013	108	36,7%	186	63,3%
2014	49	50,5%	48	49,5%
2015	104	52,5%	94	47,5%
2016	60	53,6%	52	46,4%

MG appearance per age group



Age	Prevalence	Percentage (%)
<10	21	1,0
11-20	53	2,5
21-30	158	7,5
31-40	286	13,6
41-50	281	13,4
51-60	220	10,5
61-70	408	19,5
71-80	429	20,5
81-90	225	10,7
>91	16	0,8

MG appearance per gender and per age group



Age	MEN		WOMEN	
	Frequency	Percentage (%)	Frequency	Percentage (%)
<10	4	0,5	17	1,4
11-20	13	1,5	40	3,3
21-30	16	1,8	142	11,6
31-40	40	4,6	246	20,1
41-50	50	5,7	231	18,9
51-60	97	11,1	123	10,1
61-70	253	28,9	155	12,7
71-80	261	29,8	168	13,8
81-90	132	15,1	93	7,6
>91	10	1,1	6	0,5
TOTAL	876	100	1221	100

Epidemiological data conclusions

MG is more prevalent
in women than in
men

The total number of
studied patients was
2097 individuals
across the country
since 2010 up to
September 2016

MG was more
prevalent in from
2010 up to 2013,
much declined in
2014 and 2016, and
slightly increased in
2015

MG had almost equal
appearance
percentage in all
months, with a slight
decline in December
and an increase in
July

MG appears at all
ages: children, adults
and the elderly.

MG is more prevalent
in the age groups of
30-40 and 60-80

Methodology and aim of the research questionnaire

- The health-quality questionnaire used is SF-36
- The 36 questions are grouped into 8 fields of definition-scales and study 8 meanings of health
- 51 myasthenic patients from the Greek association of MG patients (H-MGA) participated.
- The aim of the research was to study the myasthenic patients' quality of life.

	Average	Standard deviation	Minimum	Maximum	Intermediate
Scale 1 Natural function	50,8	13,0	20	80	50
Scale 2 Physical function	38,2	40,7	0	100	25
Scale 3 Emotional function	47,7	28,5	0	100	33,3
Scale 4 Energy, fatigue	48,9	14,5	5	85	50
Scale 5 Emotional wellness	50,7	18,2	4	92	48
Scale 6 Social function	52,4	25,6	0	87,5	50
Scale 7 Pain	56,8	30,9	0	100	52,5
Scale 8 Overall Health	47,2	17,0	15	80	45

Descriptive analysis of the scale rates based on the SF-36 responses

Questionnaire Results Analysis

- **Scale 1:** The patients' natural function is affected by MG (average: 50,8).
- **Scale 2:** The patients' physical function has not been notably influenced in recent years. (average: 38,2).
- **Scale 3:** The patients' mental health and emotional function is notably affected by MG (average: 47,7).
- **Scale 4:** The patients' energy is decreased and their fatigue is largely increased due to MG. (average: 48,9).
- **Scale 5:** The patients' good mood is largely affected in their daily life by MG. (average: 50,7).
- **Scale 6:** The patients' social life is influenced by MG. (average: 52,4).
- **Scale 7:** The patients' pain is at the highest assessment level of their health quality. (average: 56,8).
- **Scale 8:** The patients' general health level is largely affected by MG (average: 47,2).

Conclusions (1/2)

- Due to its low prevalence, MG falls under the health policies that Europe applies for rare diseases.
- The policies' aim is to ensure healthcare (especially because of the disease's particularity, the support of the state and society for the patients, the reinforcement of research and knowledge, the moral, social and scientific support and the development of common national actions as in Europe.
- Applying actions for rare diseases and MG constitutes a high-cost process for health policies.
- MG patients have to face several challenges, such as dealing with MG symptoms, social and professional exclusion, and the financial burden that accompanies the disease.
- Through the action policies, it is expected to improve the indexes associated with MG treatment and bring about a simultaneous improvement of the patients and their families' quality of life.

Conclusions (2/2)

- The patients' physical and mental health as well as their daily life are directly affected by MG, with the scale that expresses pain at the highest assessment level.
- From 2010 up to September 2016, a total of 2097 HIV-positive myasthenic patients were examined.
- MG appears in all age groups, with a lower appearance in children and elderly of over 80 years old.
- The disease appears in women mostly at the age group of 30-50 years and in men, at the age group of 60-80.
- The disease does not appear during a specific time of year.
- There was an appearance increase from 2010 up to 2013 and a decline from 2014 up to 2016.
- The patients come from almost every place in Greece.



THANK YOU!